

## **EDITOR'S COMMENT**

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On May 2008, the UN Convention on Rights of Persons with Disabilities came into force. Twenty nine countries are parties to the convention till date, while a further 101 have signed but not yet ratified it.

This milestone represents a huge step forward for the disability sector and for people with disabilities all over the world. It represents the shift from traditionally held views on disability and people with disabilities, to recognition of their rights which are the same as everyone else in their communities and countries. It is also recognition of the vibrant and active disabled persons' organisations that have been in existence for a long time in much of the developed world and for a lesser time in developing countries.

The UN CRPD has generated many expectations, hopes and aspirations. It is also generating debates on the concepts of rights and social justice in the field of disability, in particular on the differing understanding and application of these concepts in the developed and developing world. In this context, the distinction between the developed and developing world is sometimes artificial, as there are affluent sections of the population, including people with disabilities, in every developing country with access to similar resources as those available in a developed country. When it comes to service provision, access to services and affordability, it is more appropriate to make the distinction between resource rich and resource poor people with disabilities, regardless of whether they live in a developing or developed country. When it comes to rights and social justice however, there may be differences between developing or developed countries.

Social justice generally refers to the vision of a society where all people are treated fairly, justly and impartially with equal rights, opportunities and benefits. Such a concept will give rise to various interpretations of what is 'fair', 'impartial' or 'just', depending on who is defining it and for what purpose. It may not be possible to have objective criteria or standards for social justice that are applicable all over the world, although it seems to be generally agreed that equality and protection of rights are the most important and fundamental tenets of this concept.

In developing countries with large populations, limited resources and sometimes scant respect for human rights, perspectives on social justice can be different. For policy makers in these countries, allocation of resources where there is potential for maximum benefit for the greatest number, may take precedence over emphasis on individual rights. For many people, including people with disabilities in these countries, social justice is sometimes more about access to services and benefits, and extreme positions on any aspect of rights or social justice may be viewed with concern. For example, some disabled persons' organisations from the developed world see prevention of causes of impairment as an attack on the rights of people with disabilities to be born and to live. Many in the disability sector from developing countries, including disabled persons' organisations and families of people with disabilities, do not agree with this view.

Eventually it is important to look at what is appropriate in any given context, and not to copy or transplant ideas and concepts that have apparently been well accepted or successful elsewhere. Healthy debates on social justice, rights and legal services within the framework of the UNCRPD, as applicable within different country contexts need to be encouraged and promoted.

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**GUEST EDITORIAL**

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**CONSIDERATIONS IN THE QUEST FOR EVIDENCE IN  
COMMUNITY BASED REHABILITATION**

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**ABSTRACT**

*This paper seeks to contribute to current debate on evidence-based practice and appropriate models of disability rehabilitation for people with disabilities in developing countries. Based on the authors' experience in, and evaluation of Community Based Rehabilitation (CBR) projects and research, they provide suggestions for utilising different kinds of evidence at different levels of CBR. The paper proposes four considerations. First, at the micro level of individual rehabilitation techniques, it recommends the judicious co-opting of available evidence from conventional evidence sources. Second, at the level of service planning, it suggests the need for conducting major syntheses of CBR evaluation reports for evidence. Third, it proposes the incorporation of values with research in consideration of issues at the model level. Finally, the paper proposes that in the case of CBR and similar approaches, new conceptualisations and methodologies are required in current understandings of evidence-based research and practice, which highlight the voice of people with disabilities, their family members and communities as key sources of evidence-related data.*

**INTRODUCTION**

Common understandings of evidence-based practice usually imply the use of methods that have been selected based on a foundation of repeated comparative studies, using specific, experimental methodologies. If such criteria were applied to CBR practice, it would be necessary to have, among other things, valid and rigorous randomised controlled trials indicating statistically significant effects of CBR relative to other practice models.

Unfortunately, no such research exists. The majority of studies pertaining to CBR are theory papers, opinion articles, service descriptions and service evaluations (1, 2). While these studies have led to constructive debate on processes and issues in CBR; they have not resulted in clear evidence of efficacy, consistent practice directives, or data-informed policy. Despite this, the call for evidence in CBR remains strong. Indeed, the review of CBR, initiated by the WHO (3) identified that increasingly, “*Governments want evidence-based practices, so CBR programmes must be ready to provide evidence*” for the scaling-up of CBR globally. It might be concluded that the current lack of research evidence in CBR may be limiting its recognition, uptake and organisational support. More importantly, the lack of evidence may also be limiting the potential benefit that people with disabilities, their families and communities might derive from more evidence-informed services.

Given the gulf between evidence requirements and the current reality of CBR, we suggest that some consideration of the place and construction of evidence in CBR is warranted. While we agree that substantial evidence is urgently required within the field of CBR, we suggest that discussion on this topic may also be advanced by recognising that evidence has different forms and different applications to various levels of CBR and that there should also be consideration of different ways of determining evidence in CBR. In our opinion there are methodological, practical and philosophical issues that should be explored as CBR seeks to become more evidence based.

### **LEVELS OF CBR**

We suggest that it is important to make a distinction between levels of CBR, recognising that different ‘types of evidence’ may be relevant at different levels. These levels include: (1) discrete CBR practices and techniques, (2) CBR service delivery and (3) the broader CBR model. We also suggest that across these levels, we should also seek to include a key principle underpinning CBR, (4) that of being responsive to the voices of people with disabilities and their communities, as a key source of evidence to inform the development of CBR.

#### **At the level of CBR practices and techniques, there is a need and scope for greater evidence**

The first level in our distinction is that of the practical rehabilitation practices and techniques employed in CBR. It is at the level of provision of rehabilitation interventions with individuals

that current understandings of evidence may have greatest application. Unfortunately, as pointed out in a recent detailed review (1), and some general reviews (2), there are few studies in CBR which might be used to contribute to such an evidence base. However, these studies also imply that it may be appropriate for evidence of intervention effectiveness from outside of the field of CBR and CBR publications, to be applied in this setting. We suggest that this may be a fruitful area for further investigation. For example, evidence based practices exist for ulcer prevention and treatment in leprosy rehabilitation (4) and spinal injury rehabilitation (5). Therefore, such practices might be thoughtfully applied to CBR settings, where they are suited to adaptation with low-cost, appropriate technology strategies.

In our opinion, a key priority for CBR organisations which have a clearinghouse or data analysis capacity, should be the investigation of existing databases for evidence-based techniques that may have relevance within community contexts in developing countries. This will not simply be a matter of identifying and 'importing' all evidence based techniques, because on some occasions these may be inconsistent with community based practice, or equally, the implementation of these practices might be compromised by the realities of a community setting (6). In such an undertaking, it will be important to recognise that the context in which much evidence is determined is substantially different from uncontrolled community settings. Further, where evidence-based guidelines arise from economically developed countries, they may be quite prescriptive or bio-medical in nature, and have limited application to developing country settings (7). Conversely, it may be found that in some instances, core values held within the field of CBR (such as commitment to consumer voice, community consultation and cultural relevance) cannot be readily accommodated within certain Western frameworks for evidence (8).

Despite these caveats, we suggest that at the level of specific practices and techniques, where evidence is available and applicable, it should be prudently incorporated into CBR. For this to occur, there is a need for a coordinated research programme which could review available evidence and determine how the resultant evidence-based practices might be co-opted for use in community settings in developing countries.

**At the level of CBR service delivery, some new types of evidence are emerging**

At the service delivery level, CBR is more than simply a collection of techniques. While CBR projects have much in common, they also reflect considerable diversity. They may

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exhibit differences in organisational frameworks, management structures, staffing models and use a variety of practice approaches. This lack of uniformity across CBR initiatives results in significant complexity for attempts to establish an evidence base pertaining to CBR service delivery.

Some recent studies have sought to respond to this challenge by systematically synthesising service level evaluation reports from CBR projects. Such studies, acknowledging that the field of CBR is 'evidence poor' (lacking experimental studies, randomised controlled trials and systematic reviews), have recognised that it is also 'data rich' (having a wealth of evaluations, descriptive analysis and more subjective appraisals). This emerging area of research is seeking to respond to the challenge of making such data relevant as 'evidence' to inform CBR policy and practice (9) and evaluation (10, 11).

These studies are starting to provide a general level of evidence for policy and planning in CBR (rather than specific evidence of effectiveness of CBR interventions). The most evidence-related of these studies (9) systematically synthesised recommendations of 37 CBR project evaluation reports from 22 developing countries. Results of the synthesis indicated that key areas of weakness in CBR practice were in technical, organisational and administrative aspects of management. The study identified shortcomings in strategic leadership, personnel management and CBR training frameworks globally. Based on the evidence of evaluation recommendations, this research noted priorities for enhanced management, organisational, personnel, training and administrative infrastructure in CBR projects. It also identified that for CBR to advance, greater priority must be given to collaboration and linkages at governmental, organisational, political and community levels. Further, this evaluation synthesis revealed consistent concerns regarding the use of income generation in CBR and the way medical and clinical rehabilitation is practised in CBR. In so doing, the synthesis provided an evidence-based critique of issues that require attention in the advancement of CBR.

These findings were partially echoed in another review of evaluations (10) which found that training and training frameworks in CBR were deficient for people with disabilities and CBR workers. These emerging synthesis studies utilise a different type of evidence to inform CBR practice and policy. As a result, more informed, evidence-based CBR services may be developed over time.

**At the level of the CBR model, the ‘evidence’ foundation is informed by values as well as evidence**

At the model level, CBR has evolved considerably over time (12), it is now recognised that far from being a recipe or blueprint, it is a dynamic concept comprising multiple layers and different strategies, responding to diverse political, cultural and social contexts and different organisational and financial factors. However, the flexibility of CBR does not detract from its usefulness as a model of service delivery.

We suggest that at this level, the recognisable evidence for the CBR model should comprise a mix of principles and values as well as relevant research findings. This is timely, given contemporary definitions of evidence which increasingly include variables such as values (13) and philosophies. Our contention is that at the level of the model, decisions for or against the CBR approach should be informed by values as well as research, and that these values should be acknowledged and actively debated. There are numerous philosophical foundations that can be identified in CBR, many of which are common across all rehabilitation perspectives. We have highlighted a few examples.

First, the historical and philosophical focus of CBR was an attempt to meet the need for adequate and appropriate rehabilitation and disability services for all people in developing countries. CBR then, like other rehabilitation models is based on an understanding of the value of **rights and worth of all individuals** (14). As a result, in recognition of the disadvantage experienced by most people with disabilities, many CBR initiatives seek to enhance their rights and roles in society. **Social empowerment** of people with disabilities, family members and communities is a key value inherent in CBR (15). Again, this value is shared to varying degrees by many rehabilitation models.

The CBR model departs slightly from some other models on the importance it places on values related to community. Where possible, the CBR approach seeks to utilise and build on existing resources, and involve people with disabilities, their families and communities. It may be concluded that CBR programmes aim to be **context-specific**, influenced by social and other factors within the community (16). They provide rehabilitation, training and vocational opportunities and seek to improve integration of people with disabilities into their local communities. The ideal for effective CBR programmes is that persons with

disabilities, their families, the community, community workers and health professionals collaborate to provide services **recognising the value of the local community** (17).

Another value inherent in the CBR model is that of **community participation**. It is maintained that this principle results in greater involvement of family members and local volunteers in the rehabilitation process (18), and less travel and expense for people with disabilities. As a result, family and community members can see what they are achieving, and they can continue to participate in the social, cultural and work life of their community. The value of community participation is also linked to two other values key to CBR. First, **cultural appropriateness** – employing local human resources is more likely to result in culturally appropriate practice (eg. language, religion), and lead to the use of locally-available materials. Second, **cost-effectiveness** – the use of family and community volunteers reduces the dependence on external professionals which decreases service costs and promotes sustainability.

The focus of CBR programmes is usually to support all people with disabilities **across a community** (horizontally), rather than focusing vertically on a specific group or those with a particular disabling condition. This distinction highlights an important values issue that informs choice of model. For example, in the case of working with people with leprosy, practitioners who hold a community-oriented values framework, argue for the integration of leprosy treatments and control programmes into CBR and similar horizontal approaches (19). They express the position that a key to combating social stigma is social and service integration (20). Others who emphasise the values of specialised services prefer a traditional vertical service model for the same reason, to address the social stigma people may experience (21, 22). This highlights our suggestion that at the level of model, values need to be incorporated (along with research) into the evidence debate and decision making.

#### **AN ALTERNATIVE SOURCE OF EVIDENCE THAT MAY INFORM PRACTICES, SERVICE DELIVERY AND THE MODEL OF CBR**

Finally, we suggest that a dimension currently under-recognised in the evidence debate is that of the voice of people with disabilities, their family members and communities. Given the philosophical place of CBR (at the local, community level), there is perhaps need for a new conceptualisation of evidence that utilises responsiveness to service-users (listening to

people) as a foundational framework for an evidence base. Indeed, the newly promulgated UN Convention on the Rights of Persons with Disabilities (23) enshrines disabled people's '*full and effective participation and inclusion in society*' as one of its general principles. This should include disabled people's participation in contributing to the evidence base which will shape evidence for service delivery in the future.

Within CBR, there are increasing efforts to ensure that disabled people's voices are heard, at both the individual level and at the collective level. At the individual level, CBR is increasingly adopting the 'social model', which acknowledges the influence of social factors on disabled people's functioning and requires their active participation at all levels. At the collective level, an increasingly rights-based approach to CBR is giving disabled people's organisations (DPOs) a larger role in the initiation, implementation and evaluation of CBR programmes (24). CBR practitioners should therefore collect evidence through participatory methodologies at both of these levels.

In CBR, approaches such as participatory rural appraisal (PRA) are particularly suited to gathering evidence from disabled people and communities in CBR programmes. PRA may be described as a toolbox of research **methods** which are appropriate for communities with low levels of education and little research experience, (e.g. visual and oral methods and use of local materials which allow everyone in the community to participate). However, more importantly, PRA is a **philosophy** by which outside researchers learn from communities and encourage them to take control of the research process. In so doing they can provide information from their perspective which informs CBR service delivery. The challenge is to turn this information into evidence for practice.

While PRA is now commonly used in community development, there are added challenges when used in relation to disability. First of all, disability is rarely if ever, a priority issue for communities, so before collecting evidence from communities on disability issues, there is need for community sensitisation to disability issues. Definitions of 'disability' vary across cultures, and hidden and mild disabilities may not be recognised. Communities may only raise a narrow range of disability-related issues, such as loss of income, and not be aware of other issues such as the psycho-social effects of disability, communication problems or problems facing disabled women.

There are also a number of challenges in carrying out PRA activities with disabled people themselves, since they are often the poorest, most marginalised people in the community. Their marginalisation can exclude them from participatory processes in a number of ways – due to extreme poverty (being unable to participate due to more pressing economic needs), by being ignored or considered unimportant by more powerful people in the community, through communication problems (eg. for people with hearing or learning difficulties), mobility problems, or by being unaccustomed to forming or expressing their opinions.

At the collective level, evidence on CBR programmes can also be gained from disabled people acting through their DPOs. In some countries, DPOs have informed national policy debates on poverty reduction and debt alleviation (25), though however, this may be a long term aspiration for many others. In places where DPOs are relatively newly-established and have limited resources and capacity, genuine representation across gender, disability type, children's issues and rural-urban issues is more limited.

### **Developing participatory methodologies to gain evidence**

How then do CBR programmes go about ensuring community and disabled people's participation in collecting evidence? A CBR organisation in Cambodia, Disability Development Services Pursat (DDSP), piloted methods of enabling illiterate, inexperienced rural disabled people to lead participatory exercises to plan CBR activities (26). The research team of rural disabled people were trained in a range of PRA exercises (mapping, ranking, role-play, household surveys, Venn diagrams, etc.) and carried out surveys of disabled people and their communities in three villages. Many of the lessons learned on participation in planning CBR are also applicable to gathering evidence during a CBR project to inform practice and service delivery.

The disabled research team identified disabled people, using a set of picture cards depicting types of disability to ask villagers how many people in each category of disability there were in the village, and explore incidence of disability. They also identified disabled people's main concerns and potential project priorities through focus-group discussions and individual ranking (using a number of stones to rank importance). This method could also be used to gather evidence on the effectiveness of CBR interventions, or to compare questions of different methods of service delivery, such as service uptake and service effectiveness.

At the collective level of disabled people's participation, CBR programmers should also make efforts to include DPOs in gathering evidence on CBR. While DPOs are weak in many countries, it should be realised that they have 'the right and the responsibility to identify the needs of all people with disabilities, to make their needs known and to promote appropriate measures to address their needs (24). This is the sort of evidence that CBR services should seek, to inform service delivery.

### **Limitations in participatory methods**

Clearly there are limitations to participatory research done by village disabled people. Lack of numeracy skills necessitate additional support, low status and poor self esteem (especially of disabled women) make leadership of activities problematic, limited community development skills may inhibit the generation of village-based solutions. Further, some aspects of research such as the measurement of outcomes usually rely on specific rehabilitation skills and understanding and may best be difficult for people with disabilities and community members without substantial support. Despite these limitations, we suggest that a commitment to 'hearing' the voice of people with disabilities and community members will result in an important source of evidence for CBR.

Similarly, there is considerable scope for bias from data collected by community members (either exaggerating positive effects of a project or intervention to please others, or over-emphasising difficulties in order to persuade the project to continue). While such bias may occur in data collected by organisations and DPOs, it may be particularly evident in any project working with vulnerable and marginalised people.

Due to these potential sources of bias, CBR programmes should always cross-check participatory data gained via disabled people and communities. This cross-checking, or triangulation (27), might take place through: collecting data with a multi-disciplinary team using visual, verbal, group and individual methods, and through using a range of different sources of information (men, women, children, people with different types of disability, with different levels of exposure to the CBR project), with different connections to the CBR project.

### **CONCLUSION**

After nearly 30 years of experience worldwide, CBR is still struggling to gain recognition as a legitimate model of service-provision to disabled people. Its claims that it is an effective,

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cost-efficient, sustainable model need to be borne out by evidence. In this regard we have sought to present some considerations, and identify that there are different levels at which to explore different kinds of evidence. First, it was noted that there are promising possibilities for obtaining and incorporating evidence at the direct service-provision and CBR technique level. Second, it was identified that there are encouraging studies emerging for obtaining evidence at the CBR service-level by synthesising evaluation reports and other related documents. Third, the suggestion was raised that the incorporation of values as well as research findings in establishing evidence at the model level may also be a clarifying distinction. Fourth, we suggested that in keeping with underlying values in CBR, creative new methodologies for determining evidence should include participation at the community level, including the service-users themselves, their advocates in DPOs, and local community members. Appropriate research methods, drawn from the experience of the wider community development field, should be included alongside the earlier mentioned evidence strategies to enable the voice of village disabled people to be heard and incorporated into a unique, multifaceted evidence base for the discipline of CBR.

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**DEVELOPMENTAL ARTICLES**

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**EXCLUSION OF DISABLED PEOPLE FROM MICROCREDIT  
IN AFRICA AND ASIA: A LITERATURE STUDY**

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**ABSTRACT**

*People with disabilities are barred from microcredit schemes. A literature search on the participation of people with disabilities in microcredit schemes resulted in 16 documents. The statements, recommendations and generalisations in these documents are not supported with strong evidence and are 'expert opinions' at best. Inclusion of people with disabilities within institutional schemes and self-helping schemes is recommended throughout the world. However, these seem most affected by excluding mechanisms and inclusion numbers lag behind. The absence of people with disabilities from these two schemes makes them a less attractive option. To fulfil the current needs of people with disabilities; ad-hoc schemes should continue and even expand their work. The pragmatic solution is to work with the available resources in order to change the situation of people with disabilities.*

**INTRODUCTION**

Microcredit has become a popular instrument to promote economic empowerment among poor entrepreneurs in developing countries.

Less than 10% of the adult populations in many African countries have bank accounts, and this acts as a brake on growth and opportunity (G8 summit (1), 2005). The UN and the World Bank are developing indicators on access to microfinance, and to support national governments to maximise the productive use of remittances. They perceive microfinance as a powerful tool in reaching the Millennium Development Goals. Microcredit is a part of microfinance. Apart from microcredit, microfinance includes savings, microinsurance and other financial services. The UN launched 2005 as international year of microcredit and in 2006 Mr. Muhammed Yunus, whose imaginative microcredit scheme among poor rural women became a model for the world, received the Nobel Peace Prize. Microcredit is

increasingly recommended to improve the economic situation of people with disabilities and is promoted as an intervention that contributes to social and economic empowerment. However, people with disabilities continue to be an excluded group when it comes to socio-economic interventions like microcredit (2, 3, 4, 5). People with disabilities are expected to benefit from microcredit to the same extent – and probably more - than others. Research studies looking into benefits and barriers and supporting factors on microcredit and disability are scarce. There appears to be a general concern that people with disabilities do not access microcredit to the same extent as non-disabled peers. Simanowitz (6) described four mechanisms leading to marginalisation and exclusion of the poorest of the poor from microcredit: self-exclusion, exclusion by others, exclusion by staff and exclusion by design. Poor people's lack of confidence constrains their capacity to believe the programmes can be beneficial to them, which leads to self-exclusion. Exclusion by other members is the second excluding mechanism. Exclusion particularly in group lending (Micro Finance Institutions (MFI's), self-help groups, solidarity groups, village banking) serves as a barrier where there is an incentive for stronger people in the community to exclude the poorer ones. A core element is that all members are jointly liable for each individual's loan, which creates an increased likelihood that the poorest of the poor and more vulnerable tend to be excluded from such groups. The third exclusion mechanism is exclusion by staff. Loan and credit officers may have explicit or implicit incentives to exclude the poorest, as a result of the perception that the poorest are problematic and will create increased work burden. Sustainability is prioritised over reaching the poor, leading to exclusion of the poorest due to perceived higher risks. Exclusion by design is the last excluding mechanism. To access microcredit programmes they often demand entry fees and prior business experiences. The poorest of the poor are not able to save and have no prior business experience, so they tend to be excluded from microcredit.

It is estimated that 82 per cent of the people with disabilities live below the poverty line (7). People with disabilities are amongst the poorest of the poor (8, 9, 10, 11, 5), especially in developing countries. People in developing countries are poor largely due to external factors outside of their control. Conflict, low economy growth, unfair trading agreements, a narrow industrial base, high inflation, low levels of tax collection, poor standards of health care and education, inadequate infrastructure and corruption, all combine to drive a vicious circle of

poverty (8). People with disabilities face as many difficulties in breaking out of poverty as others, but have the added disadvantages of low access to education, training, employment and credit schemes (10).

In the microcredit world there are several schemes. Mersland makes a distinction between self-helping schemes, institutional schemes and ad-hoc schemes (2). People set up self-helping schemes themselves without the support from an organisation. A group of 15-30 people pool savings weekly or monthly. These savings are distributed as loans amongst the members. Group lending minimises administrative and transaction costs for lenders by replacing credit checks and collateral processing with self-selection of groups by borrowers. Borrowers, who are jointly liable for the loans of their group, have a vested interest in choosing trustworthy partners. Joint liability also discourages default because group members exercise peer pressure to repay. The MFIs are the institutional schemes, which have higher interest rates and high repayment expectations. Most microcredit initiatives for people with disabilities are ad-hoc schemes, which are special programmes for people with disabilities. High repayment rates are often not a major issue and interest rates are often subsidised. The focal point is more on empowerment of people with disabilities than sustainability of the organisation. Microcredit is only one of many components like training, health services, all aiming on empowerment of people with disabilities. The specific characteristics of each scheme relate to different social excluding mechanisms and different outcomes reached. To promote inclusion of people with disabilities in microcredit schemes it is important to gain insight into the existing barriers that hinder inclusion.

This paper looks at how exclusion mechanisms affect the participation of people with disabilities in, and outcomes of, institutional, ad-hoc and self-helping microcredit schemes, and presents a review of literature on this topic.

### **LITERATURE SEARCH**

Electronic databases Pubmed (<http://www.ncbi.nlm.nih.gov/sites/entrez>), Web of Science (<http://portal.isiknowledge.com>), Source (<http://www.asksource.info/index.htm>) and the microfinance gateway (<http://www.microfinancegateway.com>) were searched. Other sources were reference lists, and correspondence with leading authors. Authors and people working

in the disability field were contacted to access articles, policy documents and reports. Also, examples of lending schemes for people with disabilities were collected and used to illustrate the excluding mechanisms and outcomes from real-life experiences. The World Wide Web was searched using the terms “disability” in combination with “microcredit” and “microfinance”. The focus of this research is on microcredit alone, not in combination with other microfinance services. Articles on microinsurance were excluded.

Searching Pubmed and Web of Science using the terms “disability” in combination with “microcredit” and “microfinance” resulted in “0” hits. The term “microcredit” alone resulted in 23 hits, but none of the articles were related to disability. The search on the microfinance gateway using the term “disability” resulted in 46 articles. After excluding the articles on microinsurance and articles written before 1997 and including articles related to disability, 4 articles could be included. Searching the different reference lists of the already included documents resulted in an additional 2 articles. Through handsearching the World Wide Web, grey literature and correspondence, the final search of bibliographic databases and other sources resulted in 16 articles on microcredit schemes and people with disabilities.

Two articles are published in indexed journals (Social Science Citation Index, 2003), the other articles are case reports and theory papers. All articles can be classified as level 5; “expert opinion” (Oxford Centre for Evidence-based Medicine Levels of Evidence, 2001).

**Table 1. Overview of articles**

	<b>Article</b>		
1. Microcredit schemes for people with disabilities in general	Handicap International, 2006, (7)	Review paper	Good practices for economic integration of people with disabilities
	Handicap International, 2005, (12)	Review paper	Good practices for economic inclusion of people with disabilities in developing countries
	Hulme, D. 2000, (13)	Theory paper	Microcredit in general
	ILO D.P. 2002, (10)	Theory paper	Disability and poverty reduction strategies in general

	Jenks S. 2003, (14)	Case report	Comparative analysis on the effectiveness of socio-economic rehabilitation; Bangladesh
	Lewis C. 2004, (3)	Theory paper published in an indexed journal	Microfinance in general from the point of view of women with disabilities; Zambia and Zimbabwe
	Mersland R. 2005, (2)	Review paper	Review paper on ad-hoc, self-helping and institutional microcredit schemes in general for self-employed disabled persons in developing countries
	Mukiibi, S. N., Mulya, D. 1997, (15)	Case report	Involvement of disabled entrepreneurs in the improve your business programme; Uganda
	Thomas, M. and Thomas, M.J. 1999, (5)	Theory paper	Microcredit schemes for rehabilitation of disabled persons; Bangladesh
	Yeo, R. and Moore, K. 2003, (16)	Theory paper published in an indexed journal	Theory paper on inclusion of disabled people in poverty reduction work in general
2. Institutional schemes	Dyer S. 2003, (9)	Case report	Inclusion of disabled people in institutional schemes and an evaluation of ad-hoc schemes; evaluating Leonard Cheshire International programmes (a disability organization with 250 partner projects in 57 countries)
3. Ad-hoc schemes	Thomas M. 2000, (4)	Case report	Integration of people with disabilities in ad-hoc schemes; Bangladesh
4. Self-help schemes	Haque S 2006, (17)	Theory paper	Strategies to include people with disabilities in credit and savings

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	Thomas M. and Thomas M.J. 2002, (18)	Theory paper	programmes in general, based on the outcomes of self-helping scheme programme; Bangladesh Self-help schemes as a tool for economic empowerment of people with disabilities
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Handicap International (12) conducted a research on the inclusion of people with disabilities in developing countries. In the survey, the results of 69 completed questionnaires were presented. 50 completed questionnaires came from NGOs running ad-hoc schemes and 19 from MFI's running institutional schemes. In an other report Handicap International (7) described good practices for the inclusion of people with disabilities in developing countries. Two main approaches are used; inclusion in institutional schemes and ad-hoc schemes. Mersland (2) and Lewis (3) made a distinction in their research between institutional, ad-hoc and self-helping schemes. In the report of Haque (17) on strategies to include people with disabilities in credit and savings programmes and the report of Thomas and Thomas (5) on microcredit schemes for rehabilitation of disabled persons, there is no distinction made in schemes. Dyer (9) investigates the outcomes of ad-hoc and institutional schemes. Thomas (4) describes the results of ad-hoc schemes while Thomas and Thomas (18) and Haque (17) report on self-helping schemes. The other reports and papers discuss economic empowerment for people with disabilities in general.

The specific characteristics of each scheme are associated with different social excluding mechanisms and different outcomes, as discussed in the following sections.

## **INSTITUTIONAL SCHEMES**

These schemes are part of mainstream microfinance offered by MFIs.

### **Self-exclusion**

People with disabilities hesitate to apply for credit because they are not accustomed to it (7) and they often are not sure of a positive outcome if they were to apply (3). There seems to be a lack of self-confidence and knowledge regarding how services can be beneficial for them. During their lives, people with disabilities experience many forms of rejection and exclusion, which may affect their behaviour towards microcredit leading to self-exclusion. Accumulation

of exclusion produces even secondary incapacities e.g. lower self-esteem, which may lead to self-exclusion from microcredit by disabled people (10). Another self-exclusion mechanism is that sometimes, they expect charity grants instead of loans (12, 3, 4).

### **Exclusion by others**

Exclusion by others is described by Dyer (9). Lack of knowledge on microcredit, poor business skills/experience/financial competence and low education level are linked by others to commitment problems, leading to exclusion. Attitudinal hindrances are identified as the main obstacles perceived by people with disabilities that exclude them from the mainstream lending schemes.

### **Exclusion by staff**

The commercialisation of MFIs resulted in a mission drift away from giving poor people access, and toward credit sustainability of the organisation, which led to exclusion of people with disabilities. Alam and Haque, (19) state that banks or existing NGOs in Bangladesh (Grameen bank, BRAC or ASA) are not providing loans to people with disabilities. These institutions assume that people with disabilities would not be able to repay their loans due to their vulnerability. To develop inclusion of people with disabilities in mainstream MFIs is perceived to be time consuming, because of the specific needs of people with disabilities. Perceived extra time and additional financial costs affects the sustainability of the MFI in a negative way. Often, there is a lack of confidence in this particular target group among the staff, leading to exclusion by staff (9). Many mainstream development NGOs and MFIs continue to claim that they are not specialists in the disability field. Therefore, they do not consider disability issues (16). Mersland discovered in his research that most MFIs did not see a reason for tracking disability specifically. They explain that it would distort the work of the credit officer, whose job is to evaluate viable business and repayment capacity. It is not their job to evaluate physical ability and/or disability. The MFIs admitted that their personnel and the society in general probably have a tendency to miscalculate or underestimate the abilities of people with disabilities. A number of MFI show willingness and interest to include people with disabilities, but were not prepared to make their programmes more accessible and disability sensitive. Without these changes, hindrances to enable disabled people remain (9).

### **Exclusion by design**

The credit methodologies hinder people with disabilities from access to microcredit. To evaluate a possible client, credit officers look at personal skills and character in addition to assessing the business. However, many credit officers dealing with people with disabilities find it difficult to see through the disability and recognise the real abilities. People with disabilities continue to remain excluded from these schemes because they are a minority even amongst the poorer groups of people and because the benefits of most programmes, including savings and credit schemes, tend to get cornered by a powerful section of the group, of which disabled people are not a part. All MFIs using a group methodology admitted that this methodology might lead to the exclusion of disabled persons (2). Many of the disabled people are unable to meet the selection criteria of the providers. Lack of sufficient start-up capital, credit history and being unable to produce the collateral required, are other exclusion by design mechanisms (3, 4). Weekly payments are often identified as a higher obstacle for a disabled person than for a non-disabled person (2). There is a lack of flexibility in these credit operations to facilitate inclusion of disabled persons (4). Weekly repayment and attending meetings cause exclusion by design for people with disabilities in becoming successful entrepreneurs. Disability often comes with mobility problems. Running ones own business is difficult enough as it is for people with disabilities, without the added burden of weekly repayments and attending meetings. The design of the credit programme causes repayment problems and people with disabilities have more difficulties with keeping accounts as compared to their counterparts (12).

Inaccessible buildings, transportation problems and limited cooperation with the government are obstacles for people with disabilities in obtaining microcredit. These disability related excluding mechanisms serve as hindrances not only for access to microcredit, but are also reasons why people with disabilities often have limited access to education, training and participation in enterprise compared to the non disabled.

### **Outcomes for people with disabilities**

The studies report individual social and economic outcomes and changes within the community resulting from access to microcredit. Most respondents are confident that the programme had a significant social and economic impact. Empowerment and greater

independence led to improved social conditions. They mention increased self-reliance, self-confidence and self-esteem. Some respondents refer to their changing status in the family. They are not neglected anymore, participate in family decision-making, or even take a leading role in their family. This change of negative attitude in the community improved their social status and social integration (12, 9). People with disabilities also express that microcredit led to the establishment of sustainable economic activities, acquirement of business skills and strengthening of capacities. Access to microcredit led to improved living conditions, increased regular income and reduced vulnerability (12). Through economic empowerment borrowers spoke of being able to access better health services, improved household income, ability to buy food and nutrition and children now being able to go to school. Others mention the ability to pay for medication and school uniforms needed by their children. These are clear indicators of positive steps towards breaking the poverty and disability cycle (9).

#### **Institutional outcomes**

MFIs are experts in micro finance and run sustainable and self-sufficient institutions, with repayment rates of 90% or higher (12, 9). This makes strong and fast development possible. Their success led to increasing interest of donors and partners in the inclusive programmes. The impact in terms of disabled people and family members reached, is still relatively low (9). Many MFIs report they have people with disabilities among their clients. However, the exact number is often not known, because it is not recorded. The number of people with disabilities at the few MFIs that keep a record is between 0.5 % - 2% of all clients. The few MFIs that included some disabled people valued the inclusion of people with disabilities in their mainstream programmes (12).

Internationally, there has been a shift of emphasis on mainstream inclusion in employment and credit schemes. Unfortunately, often these policies do not take into account the existing institutional discrimination inherent in the markets (16).

#### **AD-HOC SCHEMES**

Most ad-hoc schemes are special services for disabled people provided by DPOs and NGOs.

### **Self-exclusion**

Often, people with disabilities are also familiar with the staff of ad-hoc schemes, feel more understood and less discriminated and stigmatised. This contributes to diminish the self-exclusion mechanism (3).

### **Exclusion by others**

Misinformation and prejudices put people with disabilities in a competitive disadvantage in the market (4). Stigmatisation and discrimination are mentioned as excluding mechanisms as people did not want to buy from a woman with a disability (3). Their families are often not very supportive (4).

### **Exclusion by staff**

Special training of the staff of community development programmes to identify disabled persons and deal with their disability, supports positive outcomes. The exclusion by staff is not an issue with ad-hoc schemes since they are familiar with this group (4).

### **Exclusion by design**

Because people with disabilities often experience difficulties with the exclusion by design mechanism, ad-hoc schemes often provide a flexible repayment scheme and in some instances providing interest free loans. The design of the programme demands no savings or prior experiences with loans to access microcredit (12, 3).

### **Disability related exclusion**

Inaccessible infrastructure, lack of appropriate adaptive equipment and resources, problems with transport and mobility are mentioned by people with disabilities as obstacles to successfully run their business. These mobility problems are associated with a disadvantage in marketing of their products and competing with non-disabled people (12, 3, 4). Besides these physical barriers, other constraints are low education level, low income and lack of access to information.

### **Outcomes for people with disabilities**

The programme had a significant social and economic impact according to one study (12). Indicators for improved social well-being at individual level are increased self-reliance,

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self-confidence and self-esteem. Access to microcredit and entrepreneurship resulted in a more favourable assessment of immediate environment. The social position and acceptance of people with disabilities in the community improved. Their success changed the negative attitudes of the community. The family and community respected them more than before. The community members treated them better and some community members felt that it was their responsibility to look after the disabled people. People with disabilities were more assertive after enrolment in the savings and lending scheme, which had a positive impact on their attendance in community functions (12, 3, 14). They voted in the elections unlike earlier and some became decision making members of the community group (3). They are not neglected anymore, participate in family decision-making, or even take a leading role in their family, which shows improved social integration (12).

Besides great social improvement, access to microcredit shows great effects in their economic situation. The business solutions are often imperfect. People with disabilities have additional costs and burdens due to their disability, and yet they manage (3, 9). While they experience many difficulties, most of the borrowers are making payments on their loans, sustaining and even expanding their businesses. The establishment of sustainable economic activities created increased regular income and improved living conditions of themselves and their family. The disabled entrepreneurs showed they have acquired business skills and had strengthened their capacities. Overall, microcredit reduced vulnerability and poverty and led to empowerment and greater independence for people with disabilities (12, 3)

### **Institutional outcomes**

Research on the institutional outcomes of ad-hoc schemes showed mixed results on numbers reached, sustainability and repayments.

Handicap International (12) reported large numbers of people with disabilities reached and 65% of the 43 programmes assessed that revolving funds will be sustainable. It is estimated that 63% of the 43 programmes have high repayment rates of which 15 reported repayment rates of 95-100% and 12 reported 80-90%. Dyer (9) reported opposite results; low numbers reached, unsuccessful in running a sustainable organisation and low repayment rates. The programmes researched by Handicap International (12) showed their success in mobilising people with disabilities and increased confidence of the staff in the programme, while Dyer

(9) concluded that the costs of implementing the programme were too high in relation to the outcomes achieved.

## **SELF-HELP SCHEMES**

Self-help schemes are the oldest of all schemes formed by a group of people themselves without the involvement of an organisation. Since these schemes largely exist and reach many people, these schemes fall into the mainstream schemes, together with institutional schemes.

### **Self-exclusion**

Conditions of people with disabilities are characterised by great insecurity, which often leads to risk-avoiding behaviour and lack of self-confidence. They frequently expect grants rather than self-generating income development and seem to be less motivated than others (9, 4, 18).

### **Exclusion by others**

Often, there is a fear that a powerful few in the group will hijack the benefits from others. Exclusion by others hinders people with disabilities because they are just a minority in self-help groups. Frequently their needs are viewed as a low priority by the rest and they may tend to get marginalised in a group (4, 17).

### **Exclusion by staff**

Self-help groups are formed by members themselves, exclusion by staff is thus not applicable.

### **Exclusion by design**

The exclusion by design is the main hindrance for people with disabilities to enter self-help groups (17, 6, 2). The self-selection process of members in self-help groups tends to exclude people with disabilities due to lack of awareness about the abilities of disabled people and a negative attitude and prejudice about disabled people (2). The design of the programme demands savings and attending meetings for access to credit. The attendance of people with disabilities in the group activity is lower than the others and many of the people with disabilities are very poor and therefore unable to save (18).

### **Disability related exclusion**

Group formation problems in rural areas include distances between clients. Difficult terrain makes group formation less practical, especially for people with disabilities (2).

### **Outcomes for people with disabilities**

Visibility of activities of people with disabilities in the community has a positive effect on joining in community activities (4). Other benefits are improved respect for people with disabilities from the community and their family, improved social status, self-esteem and acceptance of people with disabilities (19, 4). Group members are able to send their disabled children to school. Disabled children are considered less of a burden and they now also share meals with their family members instead of waiting for others to finish their meals and eat the leftovers (19). People with disabilities can be economically empowered with access of credit (5, 19, 17).

### **Outcomes for the self-help groups**

Costs of self-helping schemes are low with relatively high impact (4). Self-helping schemes without a facilitator who makes sure people with disabilities are part of the group; hardly reach any disabled people, due to the self-selection process (6). The exclusion of people with disabilities in self-helping schemes due to the self-selection process is not a barrier in the SARPV savings and credit programme (19). They are a DPO that provides a credit and savings programme in Bangladesh. Percentage of repayments received within one year after giving the loan is 98%. The credit for disabled beneficiaries has covered 80% of the target area. Looking at the credit programme alone, the total number of disabled borrowers is 352 (64%), and the non-disabled 200 (36%). After verifying the pass records it is found that people with disabilities are more conscious about repaying their installments than the non-disabled people (19). Though the outcomes of this particular programme are positive and the supporting factors are there, they are still an exception to the rule.

## **DISCUSSION**

Scientific research on microcredit for people with disabilities is scarce. A majority of the literature includes biases and assumptions, assertions and generalisations for which no evidence is offered. The available reports and papers are case and theory reports without

any weighting scores of the supporting factors, excluding mechanisms and outcomes. The level of evidence is an expert opinion at best. The available literature gave no insight into the relations between different types of disabilities, context and their effect on outcomes and success.

Internationally, microcredit has been recommended as an intervention to improve the living conditions of poor people. The very poor and marginalised groups of people, which include people with disabilities, tend to be excluded from access to microcredit. This paper compared institutional schemes, ad-hoc schemes and self-help schemes in relation to social exclusion. Table 2 shows the results.

**Table 2. Comparison of the excluding mechanisms in the three types of credit schemes**

	<b>Institutional scheme</b>	<b>Ad-hoc scheme</b>	<b>Self-help scheme</b>
Self-exclusion	+	—	+
Exclusion by others	+	+	+
Exclusion by staff	+	—	<b>N/A</b>
Exclusion by design	+	—	+
Disability related exclusion	+	+	+

- excluding mechanism is not present
- +
- N/A excluding mechanism is not applicable

The excluding mechanisms described by Simanowitz (6) have proven to be useful to identify the main obstacles for people with disabilities to access microcredit. There are many similarities in the recommended supporting factors to reduce the self-exclusion, exclusion by others, exclusion by staff and exclusion by design mechanism. Supporting factors such as training of the staff on abilities of people with disabilities and training of the disabled entrepreneurs in running their business and increasing their knowledge on microfinance, are mentioned the most. The only place where these supporting factors have actually been

implemented in general is within the ad-hoc schemes. All MFIs using a group methodology admitted that this design had a negative impact on inclusion of disabled entrepreneurs (2). Specific changes in the design that could lower the exclusion by design are that they should not require start-up capital or collateral and they should use a flexible repayment system. Exclusion by design is not only experienced with the institutional schemes, but also within self-helping schemes. A core element of many group schemes is that all members are jointly liable for each individual's loan, which has a negative effect on inclusion of people with disabilities in such groups. The self-selection of members tends to exclude people with disabilities, especially among the self-helping schemes. Only in one example, a large number of people with disabilities were included because a facilitator was available who ensured inclusion of people with disabilities, democratic group formation, cohesion, equal involvement and building of trust and confidence. To address the exclusion by design ad-hoc schemes use a different design. Their staff is well trained on the special needs and abilities of people with disabilities, which addresses the problem of exclusion by group mechanism. The special focus of organisations running ad-hoc schemes is dealing with the disabled community. Most of them provide training of people with disabilities together with access to microcredit.

In the literature, additional exclusion mechanisms are found for people with disabilities (7, 12, 2, 3, 9, 10, 11, 5, 15). They often have to deal with discrimination and stigmatisation, which fits within the 'exclusion by others' mechanism. In all three schemes disability related excluding mechanisms are mentioned to hinder people with disabilities from access to microcredit. Inaccessible meeting places, mobility problems, lack of useful equipment and modes of transportation are mentioned the most. Inaccessible market places are linked to a competitive disadvantage and sometimes create extra financial costs. Accessibility problems also lead to limited access to education and training.

Looking at the similarities and varieties of the three schemes, the main factor that stands out is that the outcomes for people with disabilities of institutional schemes do not differ much from the ad-hoc schemes and the self-help schemes. This suggests that microcredit brings great social and economic empowerment for people with disabilities regardless of the scheme used. Indicators for improved social well-being at individual level are increased self-reliance, self-confidence and self-esteem. Their success changed the negative attitudes of the

community and family. Access to microcredit shows vast improvements in their economic situation as well. The disabled entrepreneurs show they are able to run viable and sustainable businesses and are able to make the required repayments. The establishment of sustainable economic activities created increased regular income and improved living conditions of themselves and their families. Overall, microcredit reduces vulnerability and poverty and led to empowerment and greater independence for people with disabilities.

There is a variety in institutional outcomes. The institutional schemes in the sample reviewed score high on repayment rates, sustainability, and fast development for their clients. However, the number of disabled people in institutional schemes is very low. The institutional outcomes of ad-hoc schemes and self-helping schemes show mixed results. The DPOs that started with microcredit were not able to make their organisation sustainable. They reached a small number of people with disabilities and scored low on repayment rates. Now-a-days, more ad-hoc schemes show a positive turn in their institutional outcomes. They score high on repayment rates and reach an efficient number of disabled people. These outcomes make it possible for them to turn into viable organisations ensuring long-term sustainability. Self-help schemes are the oldest of all schemes. Costs are low and a large number of people are reached. However, the self-selection process tends to exclude people with disabilities. They are only reached if a facilitator is available to ensure inclusion of people with disabilities in the group. Only then, self-help schemes score high on the number of people with disabilities reached. Since costs are low and repayment rates high, self-helping schemes are sustainable.

## **CONCLUSION**

Most of the researchers recommend inclusion of people with disabilities in mainstream institutional credit schemes. Some also recommend self-help schemes (2, 18, 3, 9). However, the self-exclusion, exclusion by others, exclusion by staff and exclusion by design are all present, within both the institutional scheme and self-help scheme. Independent implementation of ad-hoc schemes seems as a second best solution, which should only be chosen if inclusion within mainstream microcredit is not possible. Since MFIs and self-help groups still refuse to include people with disabilities on a large scale and to fulfil the current needs of people with disabilities; ad-hoc schemes should continue and even expand their work. Research suggests, that more and more of these organisations

do reach a sufficient amount of beneficiaries and score high on repayment rates, making their organisations viable and sustainable. The outcomes of all research, regardless of the scheme used, show that microcredit has great economic and social impact for people with disabilities. Therefore, DPOs, NGOs, donor/funding organisations, and governments aiming to improve the situation of people with disabilities should ask themselves what they are willing to pay for these important gains, so that the situation of the poorest of the poor and the marginalised disabled people can change.

The main conclusion is that not much is reliably known about how microcredit works in developing countries and even less is reliably known, of the details about barriers to disabled people getting any assistance from such economic sources. There is no research available where statements are supported by strong evidence. The excluding mechanisms and outcomes mentioned in the available literature are not weighted. More research is necessary, to discover the evidence and weight of these factors.

After identifying the strengths and weaknesses of each scheme, NGOs and DPOs running ad-hoc schemes appears to be the best option for people with disabilities at this stage, since they create social inclusion, participation and empowerment. In the literature, ad-hoc schemes are seen as a second best solution but in order to fulfil the current needs of people with disabilities; ad-hoc schemes should continue and even expand their work. The pragmatic solution is to work with the available resources, in order to change the situation of people with disabilities today, meanwhile the inclusion in mainstream financing should continue to be promoted supported by the successes people with disabilities have made within the ad-hoc schemes. This twin-track approach is required to meet the rights and needs of people with disabilities, as we wait for the mainstreaming approach to evolve into real inclusion of disabled people.

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**TRAINING MANUAL ON THE HUMAN RIGHTS OF  
PERSONS WITH DISABILITIES**

Editors: Francesca Ortali and Giampiero Griffo.

The manual was produced in the project "Strengthening the Skills of the National Federation of DPOs of Mongolia in Promoting and Defending the Rights of People with Disabilities" implemented by AIFO in cooperation with DPI Italy and with the financial contribution of UN.

The whole text is available on AIFO website:

[http://www.aifo.it/english/resources/online/books/cbr/manual\\_human\\_rights-disability-eng07.pdf](http://www.aifo.it/english/resources/online/books/cbr/manual_human_rights-disability-eng07.pdf)

**ORIGINAL ARTICLES**

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**THE DEVELOPMENT OF A RESOURCE GUIDE ON  
POST TRAUMATIC STRESS DISORDER FOR RURAL  
HEALTH CARE WORKERS**

Tiziana Bontempo, Lauren Westmacott, John Paterson,  
Margo Paterson\*

**ABSTRACT**

*The purpose of this paper is to discuss the benefit of culturally sensitive education and treatment protocol for Post Traumatic Stress Disorder (PTSD) in a developing country. PTSD affects many individuals worldwide, particularly in areas of conflict. Risk factors for traumatic events for the development of PTSD are more common in developing countries. Occupational therapy (OT) and Community Based Rehabilitation (CBR) offers a unique perspective to the treatment of PTSD.*

*The authors developed a PTSD education and treatment resource guide and introduced it in a workshop format to health promoters in El Salvador in March 2007.*

*The workshop and educational resources were well received by the local health workers. The authors aimed to address the cultural differences between countries, by presenting a framework that is adaptable to specific local customs and health beliefs. This resource guide reflects a combination of the holistic views of Occupational Therapy and CBR.*

**INTRODUCTION**

The worldwide prevalence of Post Traumatic Stress Disorder (PTSD) is estimated at 8%; however, it is thought to be considerably higher in areas affected by warfare(1). It is estimated, that up to one third of the world's population will be affected by a significant traumatic event in their lifetime; 10-20% of those exposed will develop some form of stress reaction such as PTSD. Prevalence of PTSD is related to increases in unemployment, educational failure, teen child bearing, and dysfunctional marriages. At the community level, the

consequences of PTSD can be seen in a loss of productivity and a decrease in economic stability(1, 2). PTSD has been acknowledged in a number of developed countries, but has only recently been recognised as a significant issue in developing countries. Occupational Therapy which aims at enabling people to function independently in their daily lives has been used along with other treatments for PTSD; however, it may not be appropriate or feasible to apply conventional treatments in developing countries. The purpose of this paper is to discuss research relevant to PTSD, Community Based Rehabilitation (CBR), and Occupational Therapy and to describe the development of a resource guide and its application in El Salvador.

Post Traumatic Stress Disorder is a form of mental illness and is part of a group of disorders known as anxiety disorders. PTSD is unique within post-conflict populations as it requires exposure to a traumatic incident or group of events that are beyond the realm of normal human experience. A full diagnosis for the disorder requires the presence of six signs and symptoms:

- exposure to a traumatic event,
- repetitive re-experiencing of the event such as flashbacks,
- avoidance of upsetting situations and emotions,
- chronic hyper-arousal,
- severe distress and interference in daily life, and
- symptoms lasting longer than one month (3).

Symptoms of PTSD may be experienced immediately after the traumatic event; or symptoms may lie dormant and become active later in the individual's life (3). Recovery time varies significantly, with some individuals continuing to have symptoms for years and even decades following the traumatic event.

A traumatic event that has the potential to lead to PTSD is an incident that falls outside of the realm of normal daily experience. Trauma can be either physical or emotional and involve a serious threat to a person's health, well-being, sense of self, or life. Traumatic events include: exposure to war as a combatant or civilian, natural disasters such as earthquakes or tsunamis, rape, sexual or physical assault, motor vehicle accidents, work related accidents, captivity, torture, ethnic or political genocide or imprisonment, and life-threatening medical

conditions, among others(2, 3). Given these events, high risk populations for PTSD include indigenous populations, immigrants, women and child victims of domestic violence, those affected by civil war and natural disasters, individuals working in unsafe environments, and those with lack of access to medical attention for serious illness. In addition to this, compounding factors such as difficult living conditions due to poverty, disability, poor social support and refugee camps increase the risk for development of PTSD (4).

Research has been conducted to discover the psychological, emotional, social, physical, and neurological factors involved in PTSD. It's relation to anxiety disorders has resulted in many studies into the effectiveness of various medications for alleviating the symptoms of PTSD, such as Selective Serotonin Re-uptake Inhibitors (SSRI's). Other treatments that have been employed by health professionals include various forms of psychotherapy such as -Trauma-Focused Cognitive Behavioural Therapy (TFCBT), Stress Management Therapy (SMT), Non-Directive Counseling (NDC), and Psychodynamic Therapy (PDT), among others. Of these types of psychotherapy, TFCBT and SMT were found to be the most effective, with the other forms of psychotherapy not producing significant improvements in symptoms of PTSD (5); however, these treatments are usually administered on an individual basis, and therefore may not be as effective as group therapy.

When working in rural communities or developing countries, it may not be possible to treat each person individually due to time, financial and personnel constraints. In these situations, Community Based Rehabilitation (CBR) may be more beneficial. One of the aims of CBR is to develop a community's ability to provide support for its members, thereby promoting social re-integration and preventing further development of stress related mental health issues (6, 7). One strategy of CBR is the transfer of knowledge and skills through education and training (8). There are many different strategies and approaches to CBR education ranging from the provision of extensive training sessions to giving local workshops. These education programmes can be targeted to participants with varying levels of education and areas of practice(9). When preparing education programmes, it is advantageous to use existing social networks to access both trainer and trainees (10).

Access to rehabilitation services, including those in CBR initiatives, is limited for certain groups. These groups include people suffering from mental illness or other forms of mental distress (7). In the past, many CBR programmes have implemented services primarily for

people with physical injuries and disabilities; however, it has been shown that individuals who have been physically injured in a traumatic event may also experience increased risk factors and symptoms of mental illness, such as PTSD (11). It is important therefore, to provide community-based services that encompass both physical and mental rehabilitation. Based on their research on individuals with amputations due to landmines, Ferguson, et al (12), suggest that local health care workers be trained in psychosocial support skills, in order to improve service provision in areas where there are few health care options by combining physical and mental rehabilitation.

Developing countries have few resources to deal with mental health problems which are mainly due to events such as wars, natural disasters, human rights violations, weak economies, and complications secondary to serious illness. Rural areas in particular, have less access to specialised professionals (13). Mental health services in Latin America are not normally integrated within the general health system, nor are they linked with social structures in the community such as family, religious and community leaders (14). In Latin America, there is a shortage of mental health professionals that creates an even larger disparity especially in Central America where the majority of people live in rural areas and cannot access the few resources that do exist, mostly in the capital cities (15).

In many situations, Western views of appropriate treatments are thrust upon developing countries, whose cultural views do not correspond with the treatments being provided. This is the case with PTSD as demonstrated by a quote from Summerfield (6): *Although PTSD is reported to be prevalent worldwide in populations affected by war, the assumption that a Western diagnostic entity captures the essence of human response to such events anywhere, regardless of personal, social, and cultural variables, is problematic.*

While it is recognised that traumatic events and thus PTSD occur worldwide, it must also be recognised that each culture will react to these events in different ways. In some cultures, the view is that a single traumatic event can produce PTSD symptoms; however, many people in developing countries deal with chronic stressors caused by combinations of poverty, war and resulting disability. It is therefore important for foreign trained health care providers to incorporate the cultural, political and socioeconomic context of the individual country into the treatment programme (12).

Occupational Therapy and CBR share several core characteristics which indicate a close fit for occupational therapists working in CBR initiatives. These include an emphasis on client-centered practice, facilitating the capacity building of others, and the development of self-sufficiency and occupational independence (16). The mutual values placed on the process of enablement and collaboration also lend support for the combination of occupational therapy and CBR (17). Both fields recognise that individuals and communities are unique in culture and in their view of mental and physical health. Occupational therapy and CBR also share common philosophies. One of the tenets of CBR is knowledge transfer which is also important to occupational therapists who provide treatment through non-traditional educational techniques, such as: group sessions, demonstrating the use of equipment, informing the client about service options and recognising adult learning principles. Occupational therapy training programmes include physical and mental health education as well as models that guide treatment, such as the Model of Human Occupation (MOHO) and the Canadian Model of Occupational Performance (CMOP). These models present a view of an individual's performance capacity as the relationship of the environment, the occupation, and several personal characteristics (18, 19). These factors create a holistic view of disability and treatment options, which includes utilising the strengths and capacities of the entire community.

Occupational therapy theories such as the MOHO and the CMOP provide a framework for understanding the impact of mental illness and trauma on an individual and community. The MOHO was developed by Gary Kielhofner (19), as a method of describing human occupations, interactions, spirituality, and activities in the context of the physical and social environment. The model encompasses three areas which govern how humans approach and perform their daily routines and occupations. These three areas are:

1. Volition, which includes one's motivation for choosing specific occupations.
2. Habituation, the occupational patterns and roles one takes.
3. Performance capacity, the potential for performing occupations based on the physical and cognitive systems.

The CMOP was created in 1997, by occupational therapists under the auspices of the Canadian Association of Occupational Therapists. It demonstrates the dynamic interaction between three components: the person, their environment and occupation. It emphasises how change

in any area has an impact upon the whole being. The three components interact to either help or limit a person with their occupational performance. The person is at the centre, demonstrating the focus of interventions. The CMOP also recognises that spirituality is a large part of every individual. More than just religion, spirituality is understood as the person's 'sense of self' and is shown at the core; affecting the person, shaping the environment, and giving meaning to occupations (18).

Occupational therapy is a discipline which has much to contribute to PTSD survivors, whose ability to perform an occupation may be affected because of fear of re-experiencing the traumatic event. This affects a person's ability to perform daily activities, maintain or build new relationships, and their enjoyment of life. People may avoid activities that trigger memories of the traumatic experience, resulting in the person withdrawing from meaningful occupations and activities, that once brought them joy. They may also neglect personal hygiene, regular routines, and become isolated socially. Occupational therapists with an expertise in mental health can offer assistance to these individuals by developing and providing treatment options. Examples of these treatment options include Scaffa, Gerardi, Herzberg, et al's (20) proposal for a framework for the occupational therapists' role in disaster relief and participation which is general and applicable to a wide-range of situations. Other research conducted by Simo-Algado, Mehta, Kronenberg et al (21), in post-war Kosovo provides support for occupational therapy by focusing on train-the-trainer CBR initiatives. Their programme, utilising local teachers, demonstrated positive results in reducing PTSD symptoms in children.

## **METHOD**

### **Development of the Resource Guide on Post Traumatic Stress Disorder**

The authors were interested in incorporating mental health aspects into CBR initiatives, in developing countries. The topic of stress disorders, notably PTSD, was limited in the literature on developing countries. After a thorough literature review and discussion with experienced international developers, the authors designed a resource guide aimed at educating local health promoters on the disorder itself and treatment options that may be available to them.

The education and treatment resource guide on PTSD for health care practitioners working in rural and under-serviced areas, is a combination of education and treatment strategies. It

is designed as a resource to 1) improve awareness of PTSD as well as 2) to provide treatment options for community health care workers. The resource guide is intended for use in any country or area that is lacking access to appropriate health care, and was developed as a framework to be adapted to local cultural beliefs. The inclusion of sections on special considerations on cultural aspects encourages users to adapt it to their culture, needs and unique symptoms.

The creation of the resource guide was directed by philosophies central to occupational therapy and CBR. The MOHO and CMOP theories, combined with the common principles of occupational therapy and CBR, helped to provide a framework through which the symptoms and issues related to PTSD could be addressed. These principles allowed the authors to gain an understanding of the impact of mental illness and trauma on both the individual and the community.

The resource guide assumes the following:

1. It is intended for use by health care workers to gain a basic understanding of the disorder in order to detect and treat basic symptoms.
2. It does not replace treatments given by specialised professionals.
3. It is dynamic in nature and can be modified to most cultures or communities in need.

There are three sections included in the resource guide (Table 1). The first section contains education directed towards the health care workers, as well as treatment options to be utilised with community members. The second section is an appendix of simplified handouts designed to be given to community members, to help with their understanding of the disorder. The third section contains website information from relevant sources to enable further study and research by the health care workers, as well as local supervisors and policy makers.

The first section provides the health care workers with an overview of PTSD, what constitutes trauma, symptoms, and the impact on the individual and community. The next segments cover general guidelines for acute treatment, reassessment and long term treatment of both adults and children. Other sections cover coping strategies, group therapy, relaxation techniques, healthy sleeping strategies, common emotional reactions, and relapse prevention. The section on coping includes examples of positive strategies to use when dealing with

symptoms of PTSD as well as negative strategies to be avoided. The section on group therapy discusses the benefits, suggested topics, and step-by-step instructions on running group sessions. There are five relaxation techniques covered: breathing techniques, active, and passive muscle relaxation, guided imagery and meditation. Issues of sleep quality are addressed by suggesting environmental and behavioural changes. Instructions for dealing with common emotional reactions cover grief, anger, trust, and guilt. The final treatment segment, discusses the chain of behaviour and events associated with a relapse of symptoms. The design and development of the Resource Guide on Post Traumatic Stress Disorder was primarily planned for implementation in El Salvador. In order to understand the El Salvadoran situation, a brief background is provided in the next section.

#### **Application to El Salvadoran context**

El Salvador has experienced a series of events in its recent history that have the potential to cause mental

**Table 1. Contents of education and treatment Resource Guide**

<p><b>Education and treatment resource guide on PTSD for health care practitioners working in rural and underserved areas</b></p> <p><b>Contents</b></p> <p>Introduction</p> <p>Post-Traumatic Stress Disorder: Definition, Signs and Symptoms</p> <p>Acute Treatment</p> <p>Reassessment</p> <p>Long Term Treatment</p> <ul style="list-style-type: none"><li>• Adults</li><li>• Children: Includes examples of games</li></ul> <p>Coping Strategies</p> <p>Group Therapy Techniques</p> <p>Relaxation Techniques</p> <p>Healthy Sleeping Strategies</p> <p>Dealing with common emotional reactions</p> <p>Relapse Prevention</p> <p><b>Appendix:</b> Includes simplified handouts of selected topics</p> <ul style="list-style-type: none"><li>• Post Traumatic Stress Disorder</li><li>• Long Term Treatment: Adults</li><li>• Trauma in Children</li><li>• Relapse Prevention</li></ul> <p>Websites: Associations and information for additional study</p>
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health problems. The civil war between 1980 and 1992, produced years of human rights violations and massacres, resulting in physical and mental disabilities. Many suffered from an increase in anxiety, depression, sleep disturbances and flashbacks in addition to psychosomatic complaints. Land resettlements following the war has continued to create deep community divisions and promoted individual stress (22). Consequently, there has been an increase in violence, homicide as well as alcohol and drug use (22). Although all of the landmines from the civil war are reported to be cleared, gang members have begun fabricating explosive devices for criminal use (23). Landmines and explosives as well as complications from illnesses such as diabetes, have caused amputations and resulting psychological effects (12). Recent natural disasters such as the major 2001 earthquakes and floods (11) have contributed to the unstable environment and consequently to mental health issues.

There is limited data on the prevalence of mental health conditions specific to El Salvador either before, or after the war (22). In terms of PTSD, Salvadoran refugees in the United States have had symptoms such as recurring nightmares or a recurring of the traumatic event, after fleeing their country from political violence and poverty (24). The Pan American Health Organisation (PAHO) estimated that over 20% of the Salvadoran population needed mental health services after the two major earthquakes in 2001 (11). Research done by Woersching and Snyder (11) revealed that up to 67% of earthquake survivors were shown to experience mental health complaints related to physical injury, complications due to illness and loss of income. Their recommendations included educating the local communities on available resources for medical and mental health treatment, as well as improving access to these services for at risk individuals. Other research conducted in temporary camps held after the earthquake demonstrated that positive coping behaviours were directly correlated with perceived level of social support and proximity to family, friends and familiar community members (25).

The present health care system in El Salvador is composed of three sub-sectors: public, social security and private, including profit and not-for-profit services. The public sector includes various health units dispersed throughout the country, known as *Sistemas Básicos de Salud Integral* (SIBASI's). Of these, 49 offer mental health services (4). Psychosocial treatment is offered in less than 50% of these ambulatory centres. PAHO estimates that

psychosocial intervention is given to only 1-20% of the patients in the centralised psychiatric hospitals (11). There is a gap in the provision of health care between the rural and urban settings as most mental health care is centralised to the two psychiatric hospitals located in the capital (4). Forty percent of the population in El Salvador lives in rural areas (4). Due to inaccessible roads, many Salvadorans living in rural areas travel to a health care facility only for serious illnesses (26). After the war and the earthquakes, many in rural areas did not receive physical or mental health care (11).

## **FINDINGS**

### **Implementation of Health Promoter Workshops**

The authors collaborated with the Acceso project, part of the Technology Transfer Fund Canadian International Development Agency (CIDA) between El Salvador and Canada, to provide mental health workshops, with a focus on PTSD symptoms and treatment. The Acceso project was managed by the Social Programme Evaluation Group (SPEG) at Queen's University in Canada. The focus of the Acceso project was to reduce poverty and inequality for persons with disabilities, by assisting El Salvador in the implementation of CBR programmes and development of prosthetics and orthotics services (27). The authors facilitated mental health workshops in the rural areas of Santiago de Maria and Tonacatepeque, with the collaboration of a local psychiatrist and physiotherapist, and a Canadian occupational therapy consultant for the ACCESO project. Attendees of the workshop included local area health promoters as well as members of local disability groups.

The purpose of the one day workshops was to increase awareness of mental health issues affecting community members, in particular PTSD, and to educate the health promoters about simple treatment techniques. Each workshop utilised the local psychiatrist and physiotherapist in conjunction with the three Canadian occupational therapists. The workshops used several different interactive and didactic techniques. Brainstorming sessions included discussion in three areas: understanding of the types and causes of mental health conditions, issues and challenges in the community, and strategies and resources found in their rural communities. The workshops also included presentations by local survivors of different traumatic experiences, who discussed their personal experiences with disability and the resulting psychological impact. The authors presented the signs and symptoms of

PTSD as well as the treatment options available. This was followed by a practical demonstration of breathing techniques, allowing the participants to experience the benefits themselves. The local psychiatrist completed a culturally-appropriate guided imagery exercise with the group. The case study, prepared by the local psychiatrist, was based on local experience and therefore true to their culture. Group discussions took place and were followed by a general debriefing from the psychiatrist. Printed copies of the resource guide were provided to each health promoter and electronic copies to those in supervisory roles.

Evaluation was based on the full workshop and was not specific to the PTSD module. The evaluation consisted of 5 open-ended questions and was administered at the end of each workshop. The data collected were primarily based on subjective accounts from the participants. Areas such as satisfaction with the workshop, applicability of information in their daily work, areas for improvement and future workshop themes of interest were discussed. The final question was structured, asking the participants to name two principles learned from the workshop. This question yielded information on the salient features that were retained by the health promoters. The majority of the respondents felt that the workshop was very useful for their work as health promoters. One health promoter was motivated by the workshop, "I learned quite a bit on the topic of mental health in the community. I plan to use some of the strategies I learned today with my patients such as relaxation techniques, poetry writing, and physical exercise." An overwhelming majority expressed the desire to learn more about sexual and reproductive health, particularly HIV/AIDS in future workshops.

## **RECOMMENDATIONS**

Further research regarding the efficacy of the resource guide would be beneficial in order to develop the validity and reliability of the resource guide for more extensive use. Potential avenues for testing this include follow-up research involving the health promoters in El Salvador and the use of the resource guide and its effectiveness within their practice. Other options include systematic implementation and evaluation of each individual section of the module, as well as the module as a whole.

A broad spectrum of mental health problems exists in all developing countries, but for the scope and purpose of this project, PTSD was focussed upon as there are few investigations,

especially in rural areas. It also fit with goals of the Acceso project in El Salvador. Other options for future initiatives include: mood disorders, other anxiety disorders, or schizophrenia. This project was supported by the local psychiatrist and occupational therapy consultant who has extensive practical experience in El Salvador and other developing countries. The Acceso project provided an opportunity to implement the resource guide in a practical manner. Although the resource guide and presentation were initially tailored for the El Salvadoran context, it must be remembered that it is designed as a framework that can be adapted for use in most developing countries. Health care workers should first apply cultural norms and beliefs in order to make the guide effective.

The Acceso project identified the health promoter workshops as the ideal venue for presenting the resource guide. The health promoter system in El Salvador is an already established system, in which the promoters are often the first line of care in rural areas. Incorporating the study of mental health conditions into their education and training, could greatly enhance the current service provision in rural areas in El Salvador. By providing training in both physical and mental rehabilitation, the local health promoters would be better equipped to offer a continuum of treatments. This type of training could reduce the gap in services that currently exists and standardise the training across the country.

Further work in other areas of mental health would be beneficial to improve service provision in developing countries. Specifically, research into the efficacy of PTSD treatments, especially in a CBR context, could help to improve service provision. Development of consensus through repeated research studies on the same topic would support a stronger argument for providing trauma-related mental health treatments in a CBR programme both nationally and internationally. This workshop is one example of a mental health initiative. Future initiatives could include other topics in mental health presented in a form that is easily accessible by health care workers in rural areas in El Salvador and other developing countries. The ultimate goal is the prevention, treatment, and integration of people with mental illness into the community.

## **LIMITATIONS**

The authors were not able to do a needs assessment at the local level prior to developing and implementing the education and treatment module. Instead the resource guide was based on

research studies and suggested treatment options found through the literature search. Additional direction was provided through context-specific information presented by the Acceso, project manager's interviews, collaboration with an occupational therapist with international experience and a 2004 needs assessment.

Language issues hindered spontaneous discussion between the authors and the health promoters. This was addressed through the use of an experienced translator; however, this may have interrupted the flow of discussion and possibly discouraged some health promoters from seeking clarification.

The resource guide has not been tested or effectively evaluated and although the workshop evaluation contains inherent threats to validity, there was some valuable information obtained. The responses were mostly positive, but offered some information which can be used to improve the resource guide and its presentation. Cervero (28), cautions that interpretation of satisfaction questions must be done carefully, as participants are apt to answer rapidly and the answers may not be reflective of their true learning; therefore, these responses must be accepted with some caution. Many of the health promoters stated they would use the stress management and relaxation techniques described in the workshop in their daily practice. The addition of suggestions increases the value of the information provided. Many reported suggestions to improve the workshop, namely, to expand on each theme and increase the length of the workshop. Suggested topics included sexual and reproductive health, aggression, and hyperactivity disorders.

## **CONCLUSION**

PTSD is a mental illness which affects a significant proportion of the population worldwide, particularly in areas of high risk for traumatic events. Many developing countries, and in particular their rural areas, do not have the resources to deal with mental health issues. Current treatments utilised in Western countries involve individualized treatments that are time and resource consuming. The education and treatment resource guide for PTSD is an attempt to provide local health professionals with more accessible treatment ideas, especially in areas with limited service provision. It aims to address the cultural differences between countries, by presenting a framework that is adaptable to specific local customs and health beliefs. This resource guide reflects a combination of the holistic and inclusive views of OT

and CBR. Initial presentation of the resource guide at workshops in rural areas of El Salvador was well received by the local health care workers.

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## **DISABILITY AMONG CLIENTS ATTENDING TAIF REHABILITATION CENTRE, SAUDI ARABIA**

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### **ABSTRACT**

*This is a cross-sectional study of hospital records of people who were admitted to Rehab Armed Forces Rehabilitation Center, Taif, Saudi Arabia from 1999–2005. Eight hundred and fifty records were reviewed. Data were collected on age, sex, nationality, data of admission and discharge and type of disability. Univariate and multivariate logistic regression analysis were performed to determine predictors of long stay at the hospital. Trauma as an etiology of disability was more common than non-traumatic incidents among male and middle aged clients (16-45 years). Traumatic accidents mostly result in quadriplegia (72.8%). Male, single, less than 45 years old, people with traumatic accidents and people with paralytic types of disability were significantly more likely to stay longer at the hospital. Home care programme should be expanded to minimize duration of stay at the rehabilitation centres. Health education of the public would help in encouraging disabled people to adapt to daily life activities.*

### **INTRODUCTION**

Chronic disabling conditions are an emerging challenge facing developing and industrialized nations(1). Despite the growing awareness of the public, the health and education professionals about the economic, psychological and medical impact of disability, limited research has been carried out to determine pattern of disabilities in Saudi Arabia(2).

There are number of difficulties associated with conducting research on disability related issues in Saudi Arabia. Some of these difficulties are associated with the characteristics of the Saudi society such as the fact that some families feel ashamed about having a person with a disability and as a result, tend to avoid participation in such research (3). Saudi society's view of people with disabilities is based on a simple notion of disability, and

comprises helplessness, continuing dependence, being home-bound, low quality of life and lack of productivity(3). Perhaps the most important obstacle is the complete lack of appropriate epidemiological research on the general population where most disability researches done in Saudi Arabia were on disabled children(1,4,5).

Moreover, the appropriateness of the official disability statistics for determining the amount of care needed by disabled persons is a controversial issue and therefore need to be more emphasized and ascertained(6).

In addition, many disabled people require a continuous health care system, home help and other supportive services, which makes care programmes very costly. The management of disabilities requires substantial medical, educational, social and rehabilitative care(1,7,8). The cost of preventive efforts is substantially lower and thus cost-effectiveness favors the prevention approach(9).

Hospital and community-based research that determine pattern of disability among Saudi population could contribute to information about prevalence, type and distribution of disability in Saudi Arabia(4,5,10). It will also provide information for health planning and policies addressing the needs of such special group of people(10).

The present study, therefore, was conducted to identify pattern of disability among Saudi people in Taif region and to determine factors associated with long stay at the rehabilitation hospital.

## **METHOD**

This is a cross-sectional study of hospital records of people who were admitted at Rehab Armed Forces Rehabilitation center, Taif, western region of Saudi Arabia. This center includes 100 beds and belongs to Al-Hada Armed Forces Hospitals. It is the only Rehabilitation Center that belongs to Ministry of Defense. People are referred to this center from all over the Kingdom. The centre accepts people with all disabilities due to different causes (e.g., neurological, neuromuscular, muscular, traumatic, infectious or post-orthopedic surgery).

Eight hundred and fifty patient records were reviewed to determine pattern of disability among people who were admitted at the Hospital during the period from 1999 – 2005. Fifty-

four records (6.4%) were excluded either because some data were absent or the person stayed for few hours in the hospital and was then discharged either because of death or upon request of the family.

Data were collected on age, sex, nationality, date of admission, date of discharge, cause and type of disability.

At admission, family counseling is administered to discuss the expected progress of the case and duration of stay. Regular family meetings are planned. However, some people may be discharged upon request of the family.

### **Statistical Analysis**

Data were analyzed using SPSS Version 13 (Chicago, IL). Chi-square test was used to compare 2 or more qualitative variables.

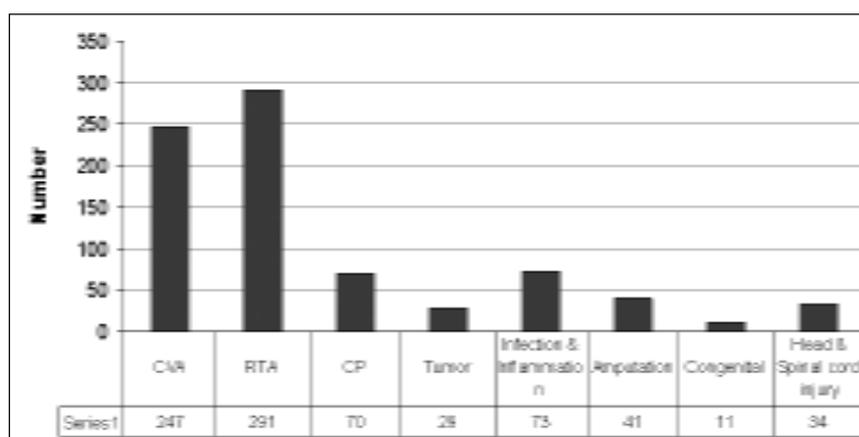
Stay at the hospital for more than 6 months was treated as the dependent variable in both univariate and logistic regression analysis. Age, gender, marital status, etiology of disability and type of disability were treated as independent categorical variables. Univariate data analysis was performed and expressed as crude odds ratios (ORs) and their confidence intervals (95% CI). Multiple associations were evaluated in multiple logistic regression model based on the backward stepwise selection, where significant variables from the univariate analysis were included. This procedure allowed the estimation of the strength of the association between each independent variable while taking into account the potential confounding effects of the other independent variables. The covariates were removed from the model if the likelihood ratio statistic based on the maximum likelihood estimates had a probability of  $> 0.10$ . Each category of the predictor variables was contrasted with the initial category (reference category). The adjusted measure of association between risk factors and job satisfaction was expressed as the odds ratio (OR) with 95% Confidence Interval (95% CI). Adjusted or crude ORs with 95% CI that did not include 1.0 were considered significant.

### **RESULTS**

About 36% of the people whose records were reviewed were 16-45 years old followed by those more than 65 years old (25.1%). There were 546 males (68.6%) compared to 250

females (31.4%). All the persons were Saudi. Regarding type of disability, 21.7% were quadriplegic, 14.4% were paraplegic, 39.2% were hemiplegic and 24.6% were complaining of other non-paralytic types of disability (e.g., LL amputation, disturbed or loss of consciousness, abnormal urination or defecation, abnormal speech and long term staying in bed). Most of them stayed for less than 6 months (90.2%). However, about 26% stayed for less than one month compared to 68.6% who stayed for 1-12 months. On the other hand, 12 persons (1.5%) stayed for 1-2 years and 32 (4.0%) stayed for more than 5 years); and no cases were reported to stay between 2-5 years (Table 1). More than one-third of disability cases were due to Road Traffic Accidents (RTA) (36.6%), followed by Cerebrovascular Attacks (CVA) (31.0%) (Figure 1).

**Figure (1) Distribution of cases according to the specific cause of disability.**



RTA= Road Traffic Accidents  
CVA= Cerebrovascular Attacks  
CP= Cerebral Palsy

Table (1) shows the profile according to etiology of disability. Trauma as an etiology of disability was more common than non-traumatic incidents among persons aged between 16 – 45 years old (73.6%), followed by those less than 15 years old (36.2%). On the other hand, 84% of those who were more than 65 years old were disabled due to some non-traumatic events, followed by 76.5% among those between 46 – 65 years old.

**Table 1. General profile of participants according to etiology of disability**

Variables	Etiology		Total N=796	p- value
	Traumatic (n=329) N (%)	Non-Traumatic (n=467) N (%)		
Age;				
15 years	42 (36.2)	74 (63.8)	116	
16-45 years	209 (73.6)	75 (26.4)	284	
46-65 years	46 (23.5)	150 (76.5)	196	
>65 years	32 (16.0)	168 (84.0)	200	0.001
Sex;				
Male	271 (49.6)	275 (50.4)	546	
Female	58 (23.2)	192 (76.8)	250	0.001
Type of Disability;				
Quadriplegia / paresis	126 (72.8)	47 (27.2)	173	
Paraplegia / paresis	47 (40.9)	68 (59.1)	115	
Hemiplegia / paresis	70 (22.4)	242 (77.6)	312	
Others†	86 (43.9)	110 (56.1)	196	0.001
Length of stay at hospital;				
1 month	38 (18.4)	168 (81.6)	206	
> 1 month-1 year	259 (47.4)	287 (52.6)	546	
1-2 years	8 (66.7)	4 (33.3)	12	
> 5 years‡	24 (75.0)	8 (25.0)	32	0.001

† others include: LL amputation, Disturbed or loss of consciousness, abnormal urination or defecation, abnormal speech and long term staying in bed.

‡ no cases reported between 2 -5 years.

Among females, disability due to non-traumatic events was significantly higher as compared to traumatic accidents (76.8% vs. 23.2 %; respectively), however, traumatic and non-traumatic events were almost equal among males (50.5% vs. 49.5%; respectively).

Traumatic accidents mostly result in quadriplegia as a complication (72.8%), while, non-traumatic events are mostly complicated with paraplegia, hemiplegia and other non-paralytic types of disability (59.1%, 77.6%, 56.1%; respectively).

Long stay (i.e.,  $\geq$  6 months) at the hospital was significantly associated with traumatic accidents. About 67% and 75% of those who stayed for 1-2 years or more than 5 years; respectively were due to traumatic accidents, while those who stayed either for less than 1 month or 1- 12 months were because of non-traumatic events (81.6%, 52.7%; respectively).

**Table 2. Distribution according to type of disability (n= 796).**

Variables	Type of disability				P- value
	Quadriplegia/ paresis (n=173) N (%)	Paraplegia/ paresis (n=115) N (%)	Hemiplegia/ paresis (n=312) N (%)	Others <sup>†</sup> (n=196) N (%)	
Age;					
15 years	48 (41.4)	28 (24.1)	31 (26.7)	9 (7.8)	0.001
16-45 years	75 (26.4)	59 (20.8)	56 (19.7)	94(33.1)	
46-65 years	34 (17.3)	10 (5.1)	110 (56.1)	42 (21.5)	
>65 years	16 (8.0)	18 (9.0)	115 (57.5)	51 (25.5)	
Sex;					
Male	153 (28.0)	71 (13.0)	205 (37.6)	117 (21.4)	0.001
Female	20 (8.0)	44 (17.6)	107 (42.8)	79 (31.6)	
Length of stay at hospital;					
1 month	32 (15.5)	30 (14.6)	83 (40.3)	61 (29.6)	0.001
> 1 month-1 year	110 (20.1)	80 (14.7)	221 (40.5)	135 (24.7)	
1-2 years	7 (58.4)	1 (8.3)	4 (33.3)	0 (0.0)	
> 5 years <sup>‡</sup>	24 (75.0)	4 (12.5)	4 (12.5)	0 (0.0)	

<sup>†</sup> LL amputation, Disturbed or loss of consciousness, abnormal urination or defecation, abnormal speech and long term staying in bed.

<sup>‡</sup> No cases reported between 2 -5 years.

Table (2) shows the distribution according to type of disability. Quadriplegia was more common among those less than 15 years old (41.4%); in contrary to other non-paralytic types of disability which affected 33.1% of persons between 16 – 45 years old. On the other hand, hemiplegia was more common in older age groups. It has occurred in 56.1% and 57.5% of those aged 46-65 years old and more than 65 years old; respectively. However, hemiplegia was the most common reported type of disability among both males and females (37.5%, 42.8%; respectively).

Persons who stayed for longer periods at the hospital (e.g., 1-2 years or more than 5 years) had quadriplegia (58.3%, 75.0%; respectively), however, those who stayed for shorter periods (e.g., less than 1 month or 1-12 months) had hemiplegia (40.3%, 40.5%; respectively).

**Table 3. Distribution of type of disability according to the specific causes.**

Causes	Type of disability				Total (n=796)
	Quadriplegia/ paresis (n=173) N (%)	Paraplegia/ paresis (n=115) N (%)	Hemiplegia/ paresis (n=312) N (%)	Others† (n=196) N (%)	
CVA‡	5 (2.0)	9 (3.6)	220 (89.1)	13 (5.3)	247
RTA‡	107 (36.7)	45 (15.5)	61 (21.0)	78 (26.8)	291
CP‡	33 (47.1)	25 (35.7)	9 (12.9)	3 (4.3)	70
Tumor	6 (20.7)	15 (51.7)	6 (20.7)	2 (6.9)	29
Infection & Inflammation	7 (9.6)	13 (17.8)	6 (8.2)	47 (64.4)	73
Amputation	0 (0.0)	1 (2.4)	0 (0.0)	40 (97.6)	41
Congenital	2 (18.2)	2 (18.2)	0 (0.0)	7 (63.6)	11
Head & Spinal cord injury	13 (38.2)	5 (14.7)	10 (29.4)	6 (17.7)	34

† LL amputation, Disturbed or loss of consciousness, abnormal urination or defecation, abnormal speech and long term staying in bed.

‡ RTA= Road Traffic Accidents; CVA= Cerebrovascular Attacks; CP= Cerebral Palsy.

Table 3 shows the distribution of disability according to the specific causes. Most of CVA cases were associated with hemiplegia (89.1%), however, most of RTA and head and spinal

cord injuries (because of traumatic injuries other than RTA) were associated with quadriplegia (36.8% and 38.2%; respectively). On the other hand, 51.7% of persons with tumors had paraplegia. Other specific causes (e.g., infection and inflammation, amputation, congenital) were mostly associated with other non-paralytic types of disability (64.4%, 97.6%, 63.6%; respectively).

Multivariate logistic regression analysis was performed to predict independent variables associated with the length of stay at the hospital. Age in years (< 45 vs. e" 45 years old), sex (male vs. female), marital status (single vs. married), etiology (traumatic vs. non traumatic) and type of disability (quadriplegia, paraplegia, hemiplegia vs. others) were included in the univariate and multivariate regression analyses.

In the univariate analysis, male, single and less than 45 years old persons were significantly more likely to stay for longer periods at the hospital than female, married and more than 45 years old persons [(crude OR= 3.41, 95%CI= 1.67-7.19; adjusted OR= 2.15, 95%CI= 1.05-4.39); (crude OR= 1.78, 95%CI= 1.08-2.92; adjusted OR= 0.66, 95%CI= 0.34-1.27); (crude OR= 2.42, 95%CI= 1.43-4.13; adjusted OR= 1.53, 95%CI= 0.87-2.71); respectively]. On the other hand, those with traumatic accidents were significantly more likely to stay for longer periods than non-traumatic cases (crude OR= 2.93, 95%CI= 1.75-4.94; adjusted OR= 1.86, 95%CI= 1.07-3.24). Regarding type of disability, persons with paralytic types of disability (i.e., quadriplegia, paraplegia, hemiplegia) were significantly more likely to stay for longer periods as compared to those with other non-paralytic types of disability (i.e., LL amputation, disturbed or loss of consciousness, abnormal urination or defecation, abnormal speech and long term staying in bed) (Table 4).

**Table 4. Predictors for long hospital stay (Univariate and multivariate logistic regression analyses).**

Dependent Variables	Length of stay		Crude OR (95% CI)	Adjusted OR (95% CI)
	6 m N (%)	> 6 m N (%)		
Age;				
45 years	372 (93.9)	24 (6.1)	1	1
<45 years	346 (86.5)	54 (13.5)	2.42 (1.43 – 4.13)*	1.53 (0.87 – 2.71)

Dependent Variables	Length of stay		Crude OR (95% CI)	Adjusted OR (95% CI)
	6 m N (%)	> 6 m N (%)		
<b>Sex;</b>				
Female	240 (96.0)	10 (4.0)	1	1
Male	478 (87.5)	68 (12.5)	3.41 (1.67 – 7.19)*	2.15 (1.05 – 4.39)*
<b>Marital status;</b>				
Married	451 (92.2)	38 (7.8)	1	1
Single	267 (87.0)	40 (13.0)	1.78 (1.08 – 2.92)*	0.66 (0.34 – 1.27)
<b>Etiology;</b>				
Non-traumatic	440 (94.2)	27 (5.8)	1	1
Traumatic	278 (84.5)	50 (15.5)	2.93 (1.75 – 4.94)*	1.86 (1.07 – 3.24)*
<b>Type of disability;</b>				
Others†	191 (97.4)	5 (2.6)	1	1
Hemiplegia/ paresis	293 (93.9)	19 (6.1)	2.48 (0.85 – 7.71)	2.89 (1.04 – 8.02)*
Paraplegia/ paresis	102 (88.7)	13 (11.3)	4.87 (1.56 – 16.14)*	5.07 (1.75 – 14.74)*
Quadriplegia/paresis	132 (76.3)	41 (23.7)	11.87 (4.34 – 35.12)*	8.91 (3.39 – 23.38)*

† LL amputation, disturbed or loss of consciousness, abnormal urination or defecation, abnormal speech and long term staying in bed.

\* p d" 0.05

## DISCUSSION

Disability is one of the most important social and economical medical issues in the community. In contrast to the developed countries, sufficient records on the current issues of disability such as the incidence and prevalence of impairment and disability and their socio-demographic properties are unfortunately unavailable due to the lack of appropriate studies in the specified area (11).

Although estimates of disability prevalence and its pattern in Saudi Arabia are very few, there are number of centres of excellence in Saudi Arabia which provide various services for disabled people (12). However, Rehab center is the only rehabilitation centre that belongs

to the Armed Medical services. It provides services to military people and their families, so all the persons included in this study were Saudi.

During the study period from 1999-2005, traumatic injuries were more common than non-traumatic incidents among persons between 16 – 45 years old. While in the other age groups (viz., < 15 years; 46-65 years; > 65 years), non-traumatic incidents were higher. This may be attributed to the specific cause of the incident, where RTA represents 88.45% of all traumatic accidents and it is more common in the middle aged people (16-48 years) (66.7%). In England, the department of transport reported that most cases of RTA (77%) during 2004-2005 were between 15-59 years old<sup>13</sup>. On the other hand, CVA which occurs in old age groups (> 45 years) (89.47%) represents 52.89% of all non-traumatic incidents.

Traumatic and non-traumatic incidents in the current study were almost equal among males. In contrast, non-traumatic incidents were much higher among females. This can be explained by the fact that only 17.2% of RTA had occurred among females compared to 82.2% among males. Meanwhile, Most of CVA affected persons were males (62.3%). Similar findings have been reported in different studies (14, 15).

RTAs and CVA have been reported in many studies to be complicated with different paralytic types of disability (16, 17). In the current study, RTAs and CVA were responsible for 67.6% of all admitted cases. This can explain there finding that paralytic types of disability represented 75.4% (600 persons) as compared to non-paralytic types (24.6%).

Christie et al (2004) and Katzenellenbogen (1995) reported that quadriplegia is the most common complication of RTAs especially in middle aged people mostly due to cervical cord injury. In the current study, most cases of quadriplegia were due to traumatic incidents, while other types of disability (viz., paraplegia, hemiplegia and others) were mainly due to non-traumatic incidents.

Traumatic injuries occur more among young males who are usually single and may find difficultly in facing the community and coping with their new life (1). Although psychological support is provided to all disabled people who attend Rehab center, some of them especially young males, may prefer to stay at the hospital. Moreover, quadriplegia as a consequence of traumatic injuries is more common among younger age group who

may require long-term care. On the other hand, hemiplegia occurred more in the older age group, so once the critical period is overcome, most hemiplegic persons are discharged upon request of their families. This is a culture-related attitude where Saudi families usually do not allow female and/or the elderly to stay in the hospital for longer periods.

The first 3 months following trauma or injury-causing disability are the most critical period when greatest recovery is thought to occur (19). Persons admitted to the Rehab hospital are expected to stay maximally for 6 months (following the Scottish Intercollegiate Guidelines, 1998) (20), before discharge, however, in the current study, 9.8% of the patients admitted during the period of the study stayed for more than 6 months, among them, 5.5% stayed for more than 1 year. Males, single, less than 45 years old and with paralytic-type of disability are more likely to stay at the hospital for longer periods. Consequently, an efficient programme for psychological support and counseling should be implemented to help this group to overcome their problems and to adapt to everyday life. Community-based educational programmes should also be provided to increase awareness of the community to deal with disabled people.

In this study, an estimate was made of the cost of care that was provided to persons who attended the Rehab center during the period of study whether through hospital care or home care programme. Each person admitted to the Rehabilitation hospital incurs a cost of about 680 Saudi Riyals (SAR) per day and on average 122,400 SAR for 6 months. Estimated costs for people who stayed for more than 6 months in this study was 82,548,600. All costs are paid by the Saudi Government.

On the other hand, during 2006, there were 128 persons in Taif region receiving home healthcare service. This service is provided to those who are discharged from the hospital and are in need for home care. A physician evaluates them before discharge for admission to the service, then a monthly visit by the physician is provided as recommended by the home healthcare team (viz., nurse, physiotherapist) who provide a weekly visit. The cost of providing home care to this group was estimated. Although this estimate is not accurate because data are not complete, a rough estimate comes to 2000 SAR per month which is equal to 12,000 SAR for 6 months. This is much less when compared to hospital care. Moreover, home healthcare would allow more people who are in need of hospital admission, to benefit.

## CONCLUSION

There are great opportunities in Saudi Arabia to develop new information about disabilities, particularly their nature, incidence, and impact on society. These research efforts could be conducted to the betterment of science and society as well as to contribute to the development of new and better services and supports for persons with disabilities and their families. Short-term experience of home care service in Rehab center is promising and its expansion to include more people in different regions of Saudi Arabia as well as implementation of health education programmes for the public would help in providing quality care and minimizing burden of road traffic accidents as a major cause of disability in Saudi Arabia.

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**PSYCHOSOCIAL AND DEMOGRAPHIC CORRELATES OF  
ACADEMIC PERFORMANCE OF HEARING-IMPAIRED  
ADOLESCENTS**

Sujata Satapathy\*

**ABSTRACT**

*Academic performance has been considered as an interactive function of many psychosocial and demographic variables. The present study attempted to explore the nature and degree of relationship between academic performance and selected psychosocial (such as, stress, self-esteem, social-emotional adjustment) and demographic variables (such as, age, parents' education and occupation, number of siblings, family income, age of onset of disability, preschool training and type of schooling). The sample consisted of 80 hearing-impaired class VIII and X students of both sexes aged 13 to 21 years of age, mostly from the lower and middle socio-economic class. A comparative group of 111 non-impaired students was also included. The Hopkin's Symptom Checklist for stress, Basavanna's Self-Esteem Scale for self-esteem, Meadow/Kendall Social-emotional Scale for social-emotional adjustment and a personal proforma for demographic variables were administered. Results showed that stress had a significant inverse correlation with academic performance of non-impaired students, whereas the relationship was low positive in case of hearing-impaired students. While social-emotional adjustment enhanced academic performance of both groups, self-esteem did not relate significantly in either case. However, many socio-demographic variables like number of siblings, socio-economic status, and age were found to have significant correlation with academic performance of hearing-impaired students. The differences were analysed in relation to the impairment specific academic problems, educational system and the vital role played by the family.*

**INTRODUCTION**

An extensive literature survey on hearing-impaired children showed that very few studies directly addressed the relationship between psychosocial factors and academic performance. Many researchers working with deaf students reported positive correlation of academic

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performance with school adjustment and behavioural problems (1), social-emotional adjustment (2, 3), and self-esteem (4). Academic performance correlated positively with every kind of positive adaptation including health, self-esteem, adjustment, social functioning and morale (5) of students having no impairments. However, the relationships were not explored systematically among the hearing-impaired adolescents. A number of researchers pointed out the facilitative role of higher socio-economic background on psychological well-being and academic achievement of children without impairment (6, 7, 8, 9, 10), as well as on adjustment (11, 12), cognitive functioning (13) and examination success (14) of hearing-impaired students. However, the number of studies addressing the direct correlation between demographic variables and academic performance are scant in the case of hearing-impaired children.

This study examined the differences on selected psychosocial (stress, self-esteem and social-emotional adjustment) and demographic variables and their correlations with academic performance of the hearing-impaired and non-impaired adolescents.

## **METHOD**

### **Sample**

A total of 80 hearing-impaired and 111 non-impaired secondary school (class VIII and X) Indian adolescents from New Delhi, were selected. Their age ranged between 13-21 years and all the students were from low and middle socio-economic family background. 91.3% (n=73) of the hearing-impaired children were congenitally deaf, 2.5% (n=2) had acquired the impairment before the age of two and remaining 6.3% (n=5) had the onset between 2-5 years of age. 98.7% (n=79) were severely impaired while 1.3% (one) had mild impairment. 96.25% (n=77) of hearing-impaired students had parents with normal hearing. Similarly, 99.09% (n=110) of the non-impaired students had parents with no handicap.

Children with additional impairments were not included. In New Delhi, there are only two schools (one residential–special school and one integrated school) providing education to hearing-impaired children till class X, so both were included. One is a fully government aided school, while the other one is partially aided school. One government school for non-impaired students was also included, to decrease the gap in socio-economic status and facilities available in the schools.

### **Variables and Tools**

Stress: Hopkin's Symptom Checklist consisting of 30 items on dimensions like somatisation (8 items), anxiety (5 items), interpersonal sensitivity (3 items), depression (7 items) and obsessive-compulsive thoughts (7 items) was used to measure stress. It is a four point rating scale and a high score indicated high stress on this scale. The Cronbach reliability of this scale was 0.74.

Self-esteem: The modified version of Basavanna's Self-esteem Scale consisting of 28 items was used for studying self-esteem. The original true-false type of response pattern was changed to a three point rating scale, on which a high score indicated low self-esteem. It had a reliability of 0.96.

Social-Emotional Adjustment: The teachers were asked to rate the students on Meadow-Kendall Social-Emotional Adjustment Scale (15), a 5-point response format. It consisted of 41 items and had a reliability of 0.89.

Demographic Variables: A personal proforma was used to get information on background variables like age, parents' education and occupation, number of siblings, family income, onset of disability, preschool training, severity of disability and parental disability status.

Academic performance: Percentage of marks in the final examinations was taken as the indicator of students' academic performance. Class VIII students appeared in the class promotional examination conducted by the school authorities, while the students in class X appeared in the national common examination for class X students.

### **Procedure**

All the scales were translated into the local language by the back translation method. The agreement between two judges was 95%. Questionnaires were administered to the non-impaired in small groups. In case of the hearing-impaired students, questionnaires were administered individually with the help of a teacher who had mild hearing-impairment and was strong in signing, finger spelling and lip reading. Data were analysed using statistics of t' test and correlation analyses.

## **RESULTS**

Before examining the correlation of academic performance with various psychosocial and demographic variables, the analysis of significance of mean difference on these variables for both the groups were done to foster understanding of the variations in relationships. Table 1 shows that significant difference was found between the hearing-impaired and non-impaired adolescents on academic performance, social-emotional adjustment, age, parents' education and occupation, and family income. The hearing-impaired students were found to be better in academics and social-emotional adjustment than the non-impaired adolescents. However, they were also found to be significantly older than the non-impaired group. While the mean age of the hearing-impaired was 16.5 years, it was 14.8 years in the case of the non-impaired adolescents. This was due to the difference between the two groups on preschool training, which revealed that almost all hearing-impaired had attained preschool, but maximum non-impaired did not have any formal preschool training. Both the groups also differed significantly on maximum demographic variables like mother and father's education, mother and father's occupation and family income. This indicated that the hearing-impaired were significantly older, had preschool experience, belonged to families with better socio-economic condition and hence, exhibited better adjustment and academic performance. However, no significant difference was between the two groups on stress, self-esteem, number of siblings and parents' impairment status, suggesting that both groups were equally stressed, had equal level of self-esteem (though the mean values on stress and self-esteem for the hearing-impaired students were slightly higher than the non-impaired group, number of siblings and had parents without any impairment).

**Table 1: Means, SDs and t' values on different Psychosocial and Demographic variables and Academic Performance**

Variables	Hearing-Impaired		Non-Impaired		t' values
	Mean	SD	Mean	SD	
Stress	56.0	11.24	54.2	13.11	0.97, ns
Self-Esteem	23.21	10.27	22.0	7.16	0.94, ns
Social-Emotional Adjustment	97.45	10.23	90.32	10.44	4.6, p<. 01
Age	2.18	.65	1.51	.54	7.44, p<. 01
No. of Siblings	2.15	.66	2.3	.68	1.5, ns
Mother's Education	3.59	1.78	1.9	1.29	7.35, p<. 01
Father's Education	4.4	1.58	3.3	1.48	5.0, p<. 01
Mother's Occupation	1.30	.74	1.09	.29	3.0, p<. 01
Father's Occupation	3.1	1.44	1.9	.95	12.35, p<. 01
Family Income	2.89	1.59	1.56	2.90	7.8, p<. 01
Parents Impairment	4.91	.48	4.87	.63	0.5, ns
Academic Performance	48.03	15.48	34.29	8.99	7.55, p<. 01

ns= non-significant

The result on correlations revealed (Table 2) that stress had significant inverse relationship with academic performance for the non-impaired group, which was quite expected, but both had low positive association in the case of hearing-impaired students. This suggested that higher stress significantly reduced performance of adolescents without any impairment but, had low facilitative effects on academic performance of the hearing-impaired students. Secondly, self-esteem did not correlate with academic performance of students in both the categories. However, good social-emotional adjustment had significant facilitative effects on academic performance of hearing-impaired and non-impaired adolescents. Results also revealed that almost all demographic variables had significant association with academic performance of the hearing-impaired students, while the number was few in the case of the

non-impaired students. Hearing-impaired students older in age and with more siblings showed poor academic performance. Socio-economic variables like, parents' education and occupation, family's income and personal characteristics like, severity of impairment, had significant positive correlation with academic performance of hearing-impaired students. This indicated that hearing-impaired adolescents who belonged to families with better socio-economic condition and those who were totally deaf, had a better academic performance. Age of onset of disability and parental hearing status did not correlate significantly with academic performance of the hearing-impaired adolescents. However, low positive correlation between these variables suggests low positive impact of congenital deafness and deaf parents on academic performance of these students.

**Table 2. Correlations between Academic Performance and different Psychosocial and Demographic variables**

Variables	Academic Performance	
	HI	NI
Stress	0.13	-0.23, p< .05
Self-Esteem	0.003	-0.16
Social-Emotional Adjustment.	0.43, p<. 01	0.43, p< .01
Age	-0.32, p<. 01	-0.06
No. of Siblings	-0.24, p<. 05	-0.17
Mother's Education	0.45, p<. 01	0.13
Father's Education	0.36, p<. 01	0.07
Mother's Occupation	0.24, p<. 05	0.13
Father's Occupation	0.42, p<. 01	0.19, p< .05
Family Income	0.43, p<. 01	0.09
Parents Impairment	0.10	-0.09
Severity of Impairment	0.23, p<. 05	----
Age of onset of Disability	0.07	----

## **DISCUSSION**

A large body of research has shown that children with hearing-impairments are at risk of more social-emotional maladjustment than their hearing peers (9, 16, 17). Contrary to these and other studies which found no significant difference between hearing-impaired and their normal hearing counterparts on social-emotional adjustment (18, 2, 19), the present finding noted significantly better social-emotional adjustment in hearing-impaired students which thus lent support to the study by Jyothi and Reddy (20). Such a finding could be due to many factors. Firstly, the social-emotional adjustment of the hearing-impaired could be related to the quality and quantity of social interactions inside the school (21), as the early placement of these children in schools was expected to help them to improve their total communication pattern (i.e. sign language, finger spelling, and gesture) and teacher- student interaction in particular, which could have affected teachers' rating of students' social-emotional adjustment. Furth (22) contended that to a large extent, schools guaranteed deaf language proficiency, strong peer and student-teacher interactions, which helped them to achieve better psychosocial adjustment. The demographic data revealed that all hearing impaired children included in the study had preschool training. Pre-schooling facilitated social interactions and social-emotional adjustment. Informal discussions with teachers revealed that the teachers had strong belief that these students and their parents were quite accustomed to the stressors associated with bringing up a hearing impaired child, and did not find social-emotional adjustment difficult when the child reached the adolescent stage, which is substantiated by the finding of Henggeler, Watson, Whelan and Malon (23). To some extent, the higher social-emotional adjustment of the hearing-impaired could be sample specific, as the hearing impaired group were a more heterogeneous group with a wide range of hearing loss. However, the finding was encouraging in a sense, that despite the equal level of stress and self-esteem between the two groups, these hearing-impaired adolescents were able to maintain good adjustment as well as academic performance.

The finding of better academic performance of hearing impaired students could be interpreted by using the individualistic theory (24), which proposed that normal surroundings tend to compound the inferiority feelings in hearing-impaired persons which makes them try hard to develop and strengthen the compensatory mechanisms to achieve superiority (exhibited in better academic performance).

The finding related to children without impairments could be sample specific related to an urban and changing milieu of a metro city like New Delhi. Another possible explanation could be the variations in academic support given by the teachers before the examination. The hearing-impaired group perhaps got more help and support from the teachers, as compared to the non-impaired students, resulting in better academic performance. Help from the schools was also bolstered by the parents, as they belonged to families with a better socio-economic condition. The finding was in contrast to the finding of Loeb and Sarigiani (25), reporting better academic performance by the non-impaired students than the hearing-impaired students which however, could be attributed to the difference in the sample characteristics of these two studies.

Results on correlations revealed that the non-impaired students who were more stressed had low academic performance. This was in line with the drive theory of Spence and Spence (26), and consistent with many research findings (27, 28, 29, 30, 10) which suggested that a higher level of stress affected level of anxiety, problem-solving skills, and thereby affected performance adversely. The relationship was low positive in case of the hearing impaired students, which indicated that the existence of pressure resulted in improved scores for these students. This was also corroborated by Srivastava and Naidu (31) reporting moderate stress to be facilitating and conducive of efficient functioning.

An anticipated finding was that good social-emotional adjustment enhanced academic performance of all students. Similarly, the finding of Rogers, Rogers, and Belanger (32) also substantiated this present finding by reporting that educational outcomes were positively associated with general adjustment to disability in hearing-impaired adolescents.

Among the hearing impaired students the older ones being in higher classes perhaps, were more worried about their future but had lesser academic competence, and hence performed poorly. They realised their inability to meet other's expectations, which affected their academic performance adversely. Another possible explanation is the possibility of some intervening variables, like talk of a sign language teacher or interpreter, to the hearing-impaired students during the final examination. This could have presented a difficulty in comprehending the question-paper and created a wide communication gap between what was asked and what the students answered in the sheets. But in the case of students at a

lower educational level, this problem was not there, as the school authorities conducted an internal evaluation.

Another interesting finding in the case of hearing-impaired students was that those with more siblings had poor academic performance. The development of language competence in hearing-impaired children requires good parent-child interactions, which become less if the number of offspring was more. As the hearing-impaired children mature and face increased linguistic and social demands, they require extra help from their family members, apparently absorbing a great amount of family time, energy, money and emotional resources. The lack of such interactions raises the risk for deaf children not to be able to reach their full potential (33).

Significant positive correlation was found between severity of impairment and academic performance of hearing-impaired adolescents, indicating deaf students to be better performers than the partially hearing-impaired, which was in contrast to the findings of Powers (14), reporting no relationship between degree of hearing loss and examination success. The difference could be attributed to the difference in sample characteristics of age and different degrees of hearing loss.

All socio-economic variables like, parent's education, occupation, and family income had significant positive correlation with academic performance of the hearing-impaired adolescents and was consistent with several studies (34, 35), that showed the role of higher socio-economic background in their psychological well-being and academic performance. For them early diagnosis and intervention, and some important decision like, school placement, pre-school experience, educational guidance at home, and interaction with the school authorities for monitoring their educational progress, etc. depended more upon parents' awareness, insight and updated knowledge and could thus facilitate their academic performance in long run. In case of students without impairments, only father's occupation had significant positive relation with academic performance. As these students belonged to a lower socio-economic background, the father 's occupation played a crucial role in managing the family, in creating educational ambitions among their children and in driving them to achieve better in academics.

## **CONCLUSION**

The implications of these findings for educational programmes and practices indicate that academic competence as well as performance could be protected till hearing impaired students complete the first qualifying examination to enter into the job world. Instead of a fixed curriculum and examination system, the provision of distance/ open examination system having more options in selecting subjects could be more beneficial for them to perform better at least at higher educational levels. Reducing the number of language based subjects and introducing subjects based more on activity and ability, into the existing curriculum could help them not only in securing good marks but also in preparing them for the job world. In developing countries like, India measures should be taken to launch programmes for parents focusing on early identification, preventive measures, pre-schooling, parent-child interaction, and the importance of small family.

Further research is needed on hearing-impaired students from residential and integrated/ fully integrated/partially integrated settings undergoing different systems of examination, and including a control group with equal socio-economic status for better generalisability of the findings of the present study.

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## **A REMEDIAL TEACHING PROGRAMME TO HELP CHILDREN WITH MATHEMATICAL DISABILITY**

C.N.Karibasappa\*, Surendranath P. Nishanimut\*, Prakash Padakannaya\*\*

### **ABSTRACT**

*Seventeen children with Mathematical Disability (MD), who were undergoing a remedial teaching programme in a special school were compared with an age-matched control group of seventeen children, also with MD, but studying in regular schools, on mathematical achievement over a period of one academic year. Both the groups were tested on mathematical skills once in the beginning and again at the end of one academic year. The ANCOVA results showed that the children who underwent remedial teaching showed significant improvement in pre-operational and operational domains of mathematical skills. This paper presents details of the remedial teaching method. (Samveda Remedial Teaching – Math; SRT-M) employed in the study.*

### **INTRODUCTION**

Specific Learning Disability (SLD) is defined as the difficulty in learning basic skills of reading, writing, and arithmetic despite adequate intelligence, exposure to adequate instruction, and absence of gross sensory, motor and neurological problems. Anywhere from 10-20% of the schoolchildren seem to suffer from SLD. Thus, in India with 180 million school children, a conservative estimate would mean that approximately 20 million children have SLD. But the classroom teachers, teacher educators, educational administrators, as well as parents are not well informed about this problem. Instead, these children are promoted from one grade to the next grade under a 'no detention' policy, a government policy to check the school dropout at primary school level, even though they do not master the grade appropriate skills or even the basic learning skills. Such children fail to proceed through the school system successfully and invariably become school dropouts at a later stage. But if they are provided with necessary remedial teaching and support, it is possible for them to successfully compete educational and employment requirements.

Though the definition of SLD includes mathematical disability (Federal Register, Department of Education part II 34 CFR-3007, USA, August 23, 1977), not many children are referred for evaluation specifically because of deficits in mathematics. Even when a child is classified a SLD, adequate assessment procedures and remediation of arithmetic deficits are rarely evident. As a result a potentially sizable number of students with arithmetic problems are excluded from the help they need (1). The situation in India is not different. Very few children are referred for evaluation specifically because of deficits in mathematics.

Most referral for special education services for potential SLD students are precipitated by delays in reading skill acquisition. A large percentage of these children, however, also have substantial problems in arithmetic skills (2, 3, 4). It is estimated that about 60% of dyslexics have some difficulty with school mathematics. Some researchers even suggest that math disabilities are as prevalent as difficulties in other academic areas (5, 6, 7, 8). But converging evidence (1, 9, 10, 11) reveals that about 6% to 7% of the school-age population suffers from mathematical disability (MD). The degree of severity may vary from simple aspects of numeracy to simple mathematical operations and higher mathematics. Despite its common prevalence, MD has not been the focus of research, as reading disability has become (12). This relative neglect is unfortunate considering that mathematics skill is important for one's success in employment, income, and work productivity even after intelligence and reading skills have been accounted for (13).

The purpose of the present study is to highlight the need for remedial teaching for children with MD and to illustrate the effectiveness of such a remedial teaching programme in helping such children. The study also presents a detailed account of the remedial teaching framework that was followed. The authors feel that there is a great need for such interventional studies in India. Majority of the Indian schools do not have a resource room facility or a special educator available. Under such conditions, children are just promoted from one grade to another grade without achieving grade level skills, which would ultimately lead to school dropouts.

## **METHOD**

### **Participants**

The study employed a pre- and post-test design with a quasi-experimental method. 17 children with MD, who were undergoing remedial teaching at Samveda Training and Research

Center®, a special school providing residential and full-time remediation to children with learning disability located in Davangere (Karnataka State, India), constituted the Experimental group (Group 1). The control group (Group 2) consisted of 17 age matched children with MD, studying at four regular schools (who do not provide any remedial teaching) in and around Davangere. Control group children were selected from a pool of 37 poor achievers studying in various regular schools after administering a screening test for SLD. All of them were studying in English medium schools, none of them had repeated any grade, but the local language was their mother tongue.

In the beginning of the academic year, Samveda preoperational and operational profile tests (pre test), designed to diagnose the Pre-Operational and Operational errors in arithmetic, were administered to both Group I and Group II. The Samveda pre-operational and operational profile tests were administered, in that order, in two sessions with a gap of 2 hours. For the whole academic year the Group- I children were taught using SRTM while Children of Group II were not taught according to any remedial programme and attended regular arithmetic classes in their respective schools. At the end of the academic year, the same tests were administered again to both the groups (post-test). A written consent by the teachers and parents was obtained for including those children in the study.

### **Testing tool**

Two test batteries were used in testing and evaluation of participants to be included in the study.

1. **Samveda Screening Profile Test** used in Samveda Research Training Centre, where the study was taken up, was used in the screening and selection of participants. The test is designed to gather information about specific learning difficulties and plan appropriate instructional strategies. The test contained both screening and diagnostic components and covers three areas: Language (Kannada/ English), Mathematics and General concepts. Language section of the test contains the following parts: I a) Identification of letters, b) Letter reading, c) Dictation (letters); II a) Words and Paragraph reading, b) Dictation (words); III a) Phoneme oddity test, b) Phoneme reversal test, c) Phoneme stripping test; IV Reading comprehension (Gap test) and V Reading comprehension test (Questions). The mathematics section contains four parts: I a) Numeral identification, b) Numeral naming, c) Dictation

(Numeral), II Pre-Operational mathematical skills, III Operational mathematical skills and IV Verbal math questions. The General concepts part contained two parts to test basic science concepts and another to test basic social science concepts.

2. **Samveda Mathematics Basic Profile Test** was the second test used. It has two sections, Section A and Section B. This test is designed to assess specific strengths and weaknesses in basic mathematical operations.

Section A contained 12 types of questions, which measure pre-operational skills, and they are arranged in an increasing order of difficulty. The 12 items are as follows:

Type I: Mark the biggest number, 5 items.

Type II: Mark the smallest number, 4 items.

Type III: What comes after, 5 items.

Type IV: What comes before, 5 items.

Type V: Put the appropriate signs (<, >, =), 10 items.

Type VI: Write the missing number, 5 items (to check the sequence concept).

Type VII: Split and Write according to place value, 5 items (Ex:  $181 = 100 + 80 + 1$ ).

Type VIII: Add, 5 items (Ex:  $100 + 30 + 5 = 135$ ).

Item IX: Write the place value of the marked digit, 5 items.

Type X: Write in ascending order, 5 items.

Type XI: Write in descending order, 5 items.

Type XII: Dictation, 10 numbers.

Section B contained the following 13 items that measure the basic operational skills.

Type I: Addition, 5 items.

Type II: Subtraction, 5 items.

Type III: Fill in the blanks, 5 items (to check the verification concept of the above two operations).

Type IV: Multiplication, 5 items.

Type V: Division, 5 items.

Type VI: Fill in the blanks, 5 items to check the verification concept in multiplication and division.

Type VII: Representing given figures in fractions, 2 items.

Type VIII: Representing given fractions in figures, 2 items.

Type IX: Separating fractions as Proper, Improper and Mixed fraction, 5 items.

Type X: Writing equivalent fraction, 2 items.

Type XI: Find the L.C.M, 2 items.

Type XII: Find the H.C.F, 2 items.

Type XIII: Simplify 10 items on simple fraction addition, subtraction, multiplication and division.

The above evaluation tools also help in sub-grouping children within a particular classroom or to form classroom groups for effective remedial planning.

## **PROCEDURE**

An experienced special educator trained to administer these tests tested children for the present study. Children were tested in a group. During session one (Preoperational skills test) the researcher requested the children to sit on benches in the middle of the class room. Then they were asked to write their name and grade before starting the test. The researchers asked them to relax and cooperate by answering a few questions related to mathematics. There was no time limit. A two-hour rest was given after the completion of the first session, before moving on to the operational skill test. The procedure was similar to the first session. Children were given a test paper and were required to fill in the answers for which there was no time limit. Children were allowed to clarify their doubts, if any.

### **Remedial teaching:**

Remedial teaching employed in the present study is the one that is practised at Samveda Research and Training Centre. This method is referred to as SRTM-Math (Samveda Remedial teaching Model-Math) in this paper. The SRTM-Math follows the following sequence: a) Error analysis, b) Developing Conceptual Base, c) Developing Language Component, d) Mastery learning and Instructional Techniques, e) Teaching Fundamental Math, f) Teaching Interface Math and g) Teaching Parallel Text.

The first four components are given priority before initiating specific remediation in Math. Fundamental math deals with Arithmetic, Algebra and Geometry. This paper deals with only the teaching of fundamental arithmetic. Algebra and geometry are outside the purview of the present study.

Each of the major steps in the remediation that was followed in this study is described below.

**a). Error Analysis:** In this first phase, the task is to tabulate the errors committed by children in doing mathematics. By merely recording answers as right or wrong one misses an opportunity to analyse at exactly what point an error occurred. By further probing, the teacher can find the precise area where the student's level of competence in a specific skill breaks down. Besides, through error analysis, a teacher is encouraged to refrain from assigning drill activities such as worksheets, which only serve to reinforce incorrect strategies (14). The error analysis helps to establish the base for planning the Individual Education Plan (IEP). The error analysis phase involves observing the child's performance in a series of tests and class room performance. STRM-Math error analysis is based on the procedure suggested by Buswell and Leonore (15). In SRTM the errors are classified into two categories viz., **Dependent errors** (e.g., applying wrong operations because of confusing the mathematical signs) and **Independent errors** (e.g., confusion with zero).

**b). Developing Conceptual Base:** SRTM-Math gives prime importance to conceptual understanding, that helps children develop logical and sequential steps while doing operations. In the initial phase, at this level, children are taught with activities and concrete objects giving them oral instructions about the operation, but later on it changes to concrete objects with written signs and instructions. Initial activities includes informal activities such as preparing shopping lists, preparing small budgets, visiting markets, making purchases etc. In classroom teaching, concrete and usually colorful objects that can be easily manipulated by children will be used to teach math principles. Children with MD have problems in comprehending the abstract nature of mathematical operations. Hence, they need explicit examples to illustrate the principles implicit in such operations. For example, children are made to understand by way of numerous concrete examples that addition and multiplication concepts involve combination and the nature of the answer is to INCREASE whereas subtraction and division concepts involve partitioning and the nature of the answer is to DECREASE. It will help the student to comprehend the logic behind computational operations. Further, concepts are taught by a variety of illustrations, in order to avoid rigidity that one may develop in learning concepts.

**c). Language Component in Remedial teaching of Math:** This is a very important component of remedial teaching, as children in India are required to learn three languages in school, which is a very formidable challenge for children with SLD. Besides, many children study in schools where medium of instructions are in English, which is not their mother tongue. In addition, many of the children in Indian schools could be first generation learners. Under these circumstances it is necessary to consider linguistic factors while framing the remedial instructions for mathematics. In SRTM-Math, the age of the learner, number of years of general schooling before joining Samveda, level of proficiency in languages and social background all are taken into consideration while deciding about the language of remediation. General approach used is to use the mother tongue in explaining the concepts, but using the English terminology as well. If the child has severe problems in mother tongue as well as in English, a mixture of the mother tongue and English is followed in the instructions. In later stages, depending on language proficiency achieved, the instructional language will switch over completely to English or to the mother tongue. As a rule, verbal problems are introduced much later in the remediation as it is required for the child to concentrate more on the numbers, the signs and the space.

**d). Mastery learning and Instructional Techniques**

In Math, each new learning skill builds on the previous learning and these are intertwined in problem solving at a higher level. SRTM-Math gives importance to concept learning followed by simple activities that reinforce the concepts best. The learning material is in a simple to complex order and each previously learnt skill is intertwined with the next skills to be learnt, so that the reinforcement of previous skills will be automatic along with the new skills. It also employs extensive real-life situations to make it easy to learn complex skills.

Mastery learning is achieved in SRTM-Math by breaking down the complex tasks into simple sub-skills to master and later on, by presentation of the complex problems with combined sub-skills. Part learning is very important in the initial stages to master each sub-skill with the help of concrete examples and activities, while later, the stress is on whole learning which comprises combination of skills. Children are allowed to master these skills at their own pace, as it is not possible to teach a prescribed math syllabus in a prescribed time to children with MD. The progress is monitored individually and the teaching is adjusted to individual speed of learning. However, in order to keep up their motivation and competitive

spirit high, SRTM-Math also follows ‘Continuous Reinforcement (CR)’ through ‘star system’ of reinforcement schemes.

**e). Teaching Fundamental Math**

This includes teaching **Pre-operational Skills and Operational Skills.**

Teaching **Pre-operation skills** consists of two parts viz., Concrete math and Concrete-abstract math.

Concrete math includes teaching **Grouping, Categorisation, Comparison and Sequencing.** All these four concepts are taught by using concrete objects, so that mathematical concept formation will become easy. Children are provided with opportunities to manipulate various objects that differed in color, shape etc., while teaching the basic concepts of Grouping, Sorting, Distribution, Column arrangement, Row arrangement, Big–Small, Long–Short, Tall–Short, More–Less, Far–Near, Thick–Thin, After–Before, Left–Right–Center, Clockwise–Anti Clockwise, Reverse Order, Ascending–Descending Order, Counting (Oral with Concrete objects) and Basic Number concepts (10 Numerals with Pictorial representation). The problems are posed in the order of increasing difficulty. Each correct response is reinforced with a score generally. These skills are an important precursor to basic operational math skills.

Concrete – Abstract Math relates the earlier mentioned concepts to numerals (with the support of concrete examples). In addition, children are taught Counting (Oral with Pictorial representation), Number Reading, Number writing, Number showing, and Skip counting.

Each remedial lesson is followed by an exercise to check how much a child has grasped and to draw future lesson plans.

Teaching **Operational math** includes the following skills: Place Value and Face Value, Fundamental facts, Addition, Subtraction, Multiplication and Division.

The concepts of place value and face value are very important in order to understand the numeration system and the algorithms of the four basic operations. It is taught initially by grouping and regrouping concrete stimuli in the form of some games. The different places are matched with specific colors while teaching place value. The development of the number of the digit is achieved with the help of their fingers. E.g., if a teacher says One thousand

fifty six students are required to point their fingers immediately corresponding to each place and write each number on paper. Children with MD find it very difficult to write numbers with zeros (e.g. 10001 for 1001). In such cases the earlier mentioned immediate reference method will work very well. A place value box is also very useful to refer higher numbers.

Another method used is the “split and write” (Expanded Notation) method. This method is used after the first level of addition. In this method, the child has to split the number according to the place values (e.g.  $180 = 100 + 80 + 0$ ) and then match the split number to the number form ( $0 + 50 + 000 + 1000 = 1050$ ,  $1000 + 000 + 50 + 0 = 1050$ , 1 Thousand + Zero Hundred + 5 tens + zero ones/units = 1050 and in later stages  $1000 + 50 = 1050$  and 1 Thousand + 5 tens = 1050). In this method, money is used as a tool to teach place values. These are often taught in some game forms to make it interesting. Strategies to tackle the Place value included Number reading from right to left, Place Reading from left to right, using fingers as reference places, number of digits in each number (e.g. one thousand contains 4 digits), Split and Write to avoid confusion with zero etc.

**Fundamental Facts:** Here, the stress is to make children develop automaticity in processing basic fundamental skills discussed earlier. As children with SLD are prone to develop inflexible primitive strategy, divergent thinking, different methods of approaching the problem will be introduced. These can be inculcated in the form of activities and games involving reproductive (retrieving answer from memory) or reconstructive using fingers, marks etc to compute strategies. In later stages, reference counting is discouraged and mental counting is encouraged. The development of effective basic facts in the classroom is achieved through timed group competitions and activity oriented teaching which would force children to rely more on automatic mental operations. Another method employed by the authors is to give children a basic-math-fact card to master. While doing computations, if they face any difficulty, they are allowed to refer to the basic-math card and thus avoid reference counting. Introducing different computer games, group competition and group discussion in the classroom as well as during free time relieve the anxiety of math. As children practise more and more to master the basic facts in different strategies, they will memorise much better. SRTM-Math encourages children to use different strategies to master the skills. A more detailed account of four basic mathematical operations, addition, subtraction, multiplication and division, is given in the following.

## **Addition**

In SRTM-Math, before introducing the two-digit addition, addition of tens and hundreds is taught. This is done to enhance mental computation and the holistic view about number. Otherwise, often such children concentrate more on the addition of basic facts in each column or row, which does not promote mental computation. For instance, when asked to add  $210 + 100$  children may continue to follow the procedure of adding  $0+0$ ,  $1+0$  and  $2+1$  column wise and then row wise. This decreases the holistic vision of knowing that the addition of zero ending numbers could be computed more easily. Children are also encouraged to make personal flash cards, which will help them to memorise basic facts in free time.

The initial addition of higher numbers without regrouping numbers, is taught by direct method as well as split-off method. Direct method involves the following steps:

- a). Arrangement of addends on a place value box card (row and column wise).
- b). Addition of each digit according to its place.
- c). Writing down the carry over number on the respective column and place.
- d). Arrive at the sum and read out the answer.

On the other hand, Split -off method is taught by two methods:

- A. a). Split addends.
- b). Arrange the split addends according to the split place values.
- c). Add respective places by adding carry over number to next place.
- d). Write the split number in combined form.
- e). Loud reading of the sum.
- B. a). Split addends.
- b). Separate the places.
- c). Add the respective places first.
- d). Add the separated places.

If the students do not get the same answer by these two methods, or if they commit any mistakes, they were asked to check their calculations again. Addition by split-off method is generally found to be more effective in enhancing the understanding of the place value

addition, as well as speed. The addition of multiple addends of same and different numbers are also introduced as they help children to understand the concept of multiplication. Addition of facts which need regrouping will be taught by converting the addition fact to 10 first and then add the remainder to it. For e.g.,  $9 + 8 = (9 + 1) + 7$ .

### **Subtraction**

The concept of subtraction is achieved through a directive method of teaching in which children are required to manipulate colorful concrete objects and develop the notion of the relationship between addition and subtraction. Before introducing higher numeral subtraction, subtraction of tens, hundreds, and thousands is taught to enhance mental computation. Addition and subtraction of same numbers exercise are also introduced at the same time, to understand the relationship between addition and subtraction operations and to start the journey towards multiplication and division. Initially, subtraction without borrowing is taught. In borrowing problems, children use place value chart. Subtraction by direct method and split-off method are also taught. In order to verify the obtained answer, children will use addition for subtraction problems and subtraction for addition problems. Subtraction of zero from a numeral and zero from a number will be taught by direct method and some strategies are taught to tackle confusion while doing computation.

### **Multiplication**

A directive method is used to teach concept and meaning of multiplication using a variety of manipulative objects, followed by pictorial representation. The mastery of multiplication of tens, hundreds and thousands is taught first. Children with MD find it difficult to remember the multiplication rules. This can be tackled by the rearrangement method. (e.g.,  $18 \times 9 = 10 \times 9 + 8 \times 9$ ).

After the multiplication of simple numbers, without borrowing, higher number (multi-digit) multiplication is introduced. Multiplication will be illustrated and taught by different methods such as addition, direct method, multiplication by addition-split method, and multiplication by subtraction split method. The general strategies taught include: Rapid addition of Similar numerals; Writing Multiplication Signs; Getting answer by rearrangement; Multiplication of zero Ending numbers; Multiplication with zero (Any number  $\times$  Zero or Zero  $\times$  Any number = Zero); Even  $\times$  Even = Even; Even  $\times$  Odd = Even; Odd  $\times$  Even = Even; Odd  $\times$  Odd = Odd; and One  $\times$  any number = Number itself.

### **Division**

Money and some pictorial representations are used to teach division. By using money one can teach division with and without remainder division problems concretely. The rules of division are taught explicitly and students are given a reference card to use in the initial stages. Verification is taught by combining multiplication and division computation principles. The general strategy followed include Rapid Distribution (Subtraction) of Similar numerals, Writing Division signs, Rules for Division, Getting answer by rearrangement, Rules for zero division, and Division of zero ending number.

Within the framework of SRTM-Math explained earlier, IEPs are made for each student, depending upon his or her special needs and other related factors such as speed of learning.

### **RESULTS AND DISCUSSION**

In order to adjust the initial difference between the experimental and control groups on math achievement scores the authors employed Analysis of Covariance (ANCOVA) making the initial scores as covariate. Pre and Post tests scores on pre-operational and operational mathematical skills were used separately. The results of ANCOVA for pre-operational mathematical skills and operational mathematical skills followed by descriptive statistics for pre-and post-test measures are presented in Tables 1-4 respectively.

**Table 1. Summary of ANCOVA (Dependent Variable: Pre-operational skills)**

<b>Source</b>	<b>Type III</b>	<b>df</b>	<b>Mean Square</b>	<b>F</b>	<b>Significance</b>
	Sum of Squares				
Group	1454.474	1	1454.474	78.079	0.0001
Error	577.479	33	18.628		
Total	92369	34			

**Table 2. Summary of ANCOVA (Dependent Variable: Operational skills)**

Source	Type III	df	Mean Square	F	Significance
	Sum of Squares				
Group	1385.964	1	1385.964	65.901	0.0001
Error	630.931	33	21.031		
Total	27884	34			

**Table 3. Descriptive Statistics: Pre-test measures**

	N	Mean	S.D
Group I (Experimental): Preoperational test	17	49.41	13.41
Group I (Experimental): Operational test	17	15.65	10.12
Group II (Control): Preoperational test	17	34.24	9.16
Group II (Control): Operational test	17	9	5.89

**Table 4. Descriptive Statistics: Post-test measures**

	N	Mean	S.D
Group I (Experimental): Preoperational test	17	63	9.09
Group I (Experimental): Operational test	17	36.29	13.8
Group II (Control): Preoperational test	17	36	9.82
Group II (Control): Operational test	17	10.65	5.69

Results clearly reflect the effectiveness of SRTM-Math in bringing out significant improvements on both pre-operational and operational skills of mathematics (F is highly significant in both the cases) even after statistically controlling for the initial differences between the experimental group that was exposed to remedial teaching and the control group of children with MD, who did not get remedial teaching support. The purpose of the paper was to explain the remedial teaching method that was adopted as much as to show its effectiveness. The results also suggest the need for special remedial teaching support to

millions of children with SLD who attend regular schools. In the absence of any such support, children in such schools are moving from one grade to the next higher grade without mastering the necessary academic skills. It should be a serious concern of teachers, administrators and the government to realise the gravity of the problem and take appropriate measures.

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**BRIEF REPORTS**

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**COMMUNICATION FUNCTIONS IN CHILDREN WITH SEVERE  
SPEECH AND PHYSICAL IMPAIRMENT**

Preeja Balan\*, R. Manjula\*\*

**ABSTRACT**

*Children with cerebral palsy, especially with severe speech and physical impairment (SSPI) have limited access to explore the environment and develop communication skills based on this exploration. In spite of the severe limitation imposed by the condition, these children manage to communicate. The study analyzed video recorded samples of the communication interaction of 4 children with SSPI during instructed play with their mothers. The sample was judged by 2 experienced speech language pathologists for the range and frequency of communication functions namely; request for information, request for attention, request for object, information, instruction (for action), confirmation and denial. Findings of this study revealed a higher proportion of information (58%), followed by denial (29%) and then by request for object (10%). Request for information, instruction (for action) and request for attention were found minimally and in equal proportion (1%) in their communication repertoire. The findings provide baseline information of the varied communicative functions existing in children with SSPI. Clinical implications of the same are discussed.*

**INTRODUCTION**

Communication refers to the "transmission of meaning from one individual to another, whatever the means used" (1). Communication development in typically developing children is based on the following assumptions.

1. The development stages of language and communication is same in all typically developing children. (2, 3). However they could differ in terms of rate and quality of development (e.g., early vocabulary preferences).
2. The conceptual and linguistic development in typically developing children reflects a sequence of built-in priorities (3). A child generally acquires the simpler linguistic structures before the complicated ones are learnt.

3. During the developmental period, nonverbal and verbal language is acquired in a similar manner and runs parallel to other motor milestones. Certain communicative functions in the earlier period is attained through nonverbal or simpler linguistic ability (e.g., requests, greetings, and labels can be expressed nonverbally) whereas certain functions, for e.g. repair strategies require higher order language (4).

The major achievement in the prelinguistic stage, as Bates (5) states, is the emergence of intentional communication in which the child uses signal deliberately to have a pre-planned effect on the caregiver. Investigators such as Harding and Golonkoff, (6), Coggins and Carpenter (7), in their study observed that children used various communicative functions, namely request for object, request for action, protest, and comment on object and comment on action. Beginning at about 9 months of age, children have been found to express using a wide variety of intentions.

An important factor in the child's language development period is the contribution of primary care givers namely the mothers. Studies of parent-infant interactions have documented a sequence of activities, whereby parents carefully study their infant's facial expressions, movements and vocalisations as though they were social signals (8). It is during these early interactions that many critical language processes receive a boost and are encouraged, such as the desire to engage in playful vocalisation including vocal exploration, the emergence of turn taking and dialogue structure, and the desire to imitate vocal patterns.

Iacona and Carter (9) stressed the important role of the communication partner in distinguishing intentional from preintentional communication. They state that the communication partner's responsiveness and sensitivity plays an important role in identifying such differences. Wilcox, Kouri and Caswell (10), observed that the partner must consistently recognize a child's communicative or potentially communicative attempt and respond to these attempts in a contingent, appropriate and consistent manner.

Depending on the severity of the condition, children with cerebral palsy face limitation in speech and physical development. Physical impairment causes difficulties in attaining motor milestones and in turn causes physical limitations. Physical limitations in children with cerebral palsy, as explained by Cress, Linke, Moskal, Benal, Anderson and LaMontagne (14), diminish the opportunities for exploration and object-based play. Since most of the

early language learning involves physically acting on the environment, learning language through exploration is hindered. Thus, children with cerebral palsy acquire language in a different manner especially when the limited speech is accompanied by motor and /or sensory limitations affecting their ability to explore the environment around them (12, 13, 11).

Children with severe physical impairments often rely on vocalisations, eye-gaze, and gestures in their interactions with communication partners (14). However their ability to use the same is limited resulting in difficulty of the caregiver to read these signals (15). Pennington and McConachie (16) studied the interactions between mothers and their severely physically disabled children in the age ranges of 2-10 years of age whose speech was unintelligible out of context to their parents and were using aided communication systems. Children across the age range produced more response moves than any other type. Their responses contained more of yes/no answers and acknowledgements and to a lesser extent provisions of information. Most of their communicative attempts, especially for simple confirmations, denials, and acknowledgements were not completely understood and were usually followed by requests for clarifications by the mothers. Children produced a wider range of communicative functions in the semi- scripted elicitation conversation with the clinician than in conversation with their mothers. Though this study provides information on various forms of communication elicited by physically disabled children, with different partners namely mothers and clinicians, these findings cannot be generalised to children who do not have aided communication system. It is quite likely that such functions exist because of the presence of the devices.

Physical impairment along with limitation in speech permits a different exposure to children during developmental period. This study aims to analyse communication functions in children who are dependent on naturally available nonverbal communication system to view the different kinds of functions used while they interact with their mothers.

## **METHOD**

The aim of the study was to analyse the communication functions in SSPI children between 2 to 3 years of age using unaided communication strategies, while interacting with their mothers. Typically, developing children around the age of 2 to 3 years attain most of the motor milestones including speech and have fairly good language ability (7, 17, 18). But

children with SSPI lag behind their typically developing counterparts due to their inherent physical and communicative ability. This study attempts to explore the communicative functions that are observed in this population, in the absence of speech and concurrent physical impairment.

The communication functions studied are as follows:

1. Request: a. Request for information, b. Request for attention, c. Request for object
2. Information
3. Instruction (for action)
4. Confirmation
5. Denial

The sample was selected from centres providing to services for children with special needs. Children within the age ranges of 2 to 3 years with the primary diagnosis of cerebral palsy confirmed by the medical professionals and physiotherapist/occupational therapist were selected. The demographic details of the children are presented in Table 2. None of them had undergone any formal speech and language intervention. All the subjects were quadriplegic (four limbs involvement) and were not independently mobile. Their peripheral hearing and vision were normal (as per the reports available) and had age appropriate receptive language based on Receptive Expressive Emergent Language Scale, (19). They were exposed at home to the local language. Expression was primarily through non-verbal modalities and none of them had meaningful speech in their expressive vocabulary. Since there are no standardised tools available for measuring non-verbal expressions, expressive language was mainly profiled based on clinical observation and parental interview. Expression was mainly through use of unaided communication strategies such as gestures, pointing, facial expression and/or voicing.

**Table 2. Demographic data of the subjects**

<b>Subject</b>	<b>Age/Sex</b>	<b>Diagnosis</b>
A	3.0 yrs/F	Spastic Quadraplegic
B	2.10 yrs/M	Spastic Quadraplegic
C	2.6 yrs/M	Spastic Quadraplegic
D	2.11yrs/M	Dyskinetic Quadraplegic

Mothers were selected as communication partners, as they accompanied most of the children attending the intervention programme. Mothers were in the age range of 21-25 years and they were literate with a primary education of higher secondary grade. They had no speech, language or other sensory deficits.

### **Procedure**

The four dyads were familiarised with the clinical settings. The principal investigator built a rapport with the mother-child dyad. They were instructed to interact with the child using an available set of materials/toys, as they would normally do at their homes. Few sessions of feeding, physiotherapy/infant stimulation and play were video recorded to familiarize the dyad with the recording procedure and to desensitise them to the physical presence of the investigator during video recording, and to help overcome shyness/fear. Informed consent was obtained from mothers for video recording, prior to their inclusion in the study. The actual procedure consisted of 3 audio-video taped sessions of 15 minutes of each dyad interacting with the selected toys and suggested activities.

Before the recording, mothers were instructed on how to use the material and the activity that was required to be carried out with the child. A semi-structured interaction mode was chosen primarily to increase the chances of occurrence of communicative function, which were intended to be studied. The toys were selected such, that it suited the age, physical condition of the child and that which provided better communication interaction in the dyad. The same toys were provided to all the dyads. The material included ball, building blocks, car, noisemakers, marker pens, kitchen set, doll and accessories of doll, cars, papers,

flash cards and picture books. Three sessions were chosen to provide maximum opportunity for a communicative function to occur, and to rule out the contextual limitation (as in selection of a particular toy). Three audio-video recordings were carried out on separate days, within a period of one month, with a gap of a week between consecutive recordings.

**Phase1:** Mothers used both verbal and nonverbal strategies to communicate. Due to the inherent difficulty in transcribing the verbal and nonverbal behaviours of the mothers separately and since the aim of the study was to analyse mothers' overall communication strategies; only the verbal behaviours of mothers were transcribed. Child's communication strategies were not noted down in this transcription. Taxonomy of the communicative functions was based on review of literature on mother child communicative interaction (15, 20). Two judges, who were postgraduates in speech-language pathology with a minimum of 2 years of experience in intervention of childhood language impairment, were selected. A list of communicative functions, along with the definition and examples were coded for training the judges. A sample video recorded clip of a 6-year-old child meeting all the criteria as specified for subject selection in this experiment except for the age, was selected for practise purpose. This recording was used to familiarise and train the judges with respect to the terminology and coding procedure. Both the judges were trained for a period of 4 hours. The judges were given enough opportunity and practice along with ample discussion to familiarise them with the actual rating procedure.

**Phase 2:** After the training phase, the actual experiment involved the judges viewing the transcribed version of each session along with the recording of each dyadic session completely for 2-3 times. Once the judges were comfortable and were familiarised with the dyadic sessions, each transcribed utterance of the mother was coded based on the taxonomy of communicative functions provided to the judges. Similarly the recording was viewed again for coding communicative function elicited by the child. Finally, the recording was viewed in total, to reconfirm and check the coding offered for the mother and the child's communicative functions. Both the judges carried out this procedure separately, with the principal investigator helping them with the technical aspects of the recorded samples like switching off the sample at a particular point so that they could code the utterance. No discussion regarding the coding, with the principal investigator was entertained during this process. Both the judges rated the sample separately.

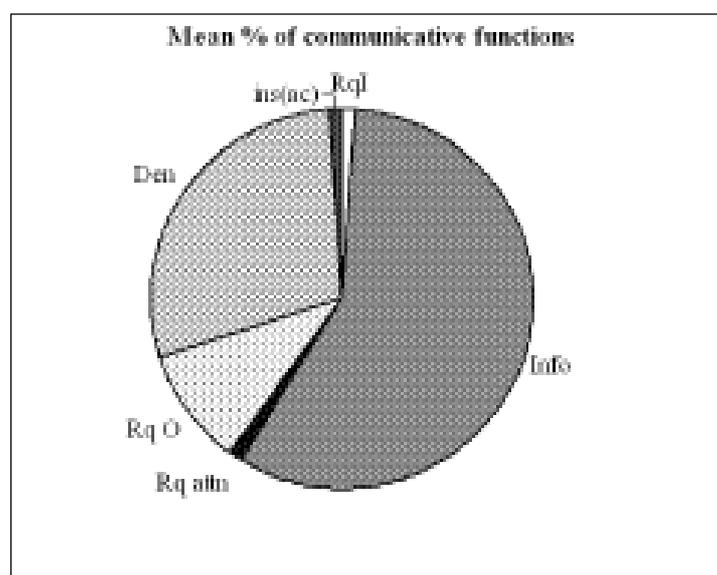
### Scoring and reliability

The frequency of occurrence of communicative function of the child was calculated. The percentage ratio was calculated as child elicited function to total child function. Inter-judge reliability using alpha co-efficient, for the communicative functions of the child was found to be 80%. Mean percentages for the three recordings were calculated for each judge. Since the inter-judge reliability of the total of the frequency functions was high (99%), the mean percentages of each judge were further tabulated to provide a composite mean rating for each communicative function, for all the 4 subjects.

### RESULTS AND DISCUSSION

The mean percentage of various functions is represented in Graph 1.

**Graph 1: Mean percentage of communicative functions in children with SSPI**



(**RqI**: Request for information; **RqO** Request for object; **Rq attn**: Request for attention; **Ins (ac)**: Instruction for action; **Info**: Information; **Den**: Denial)

In spite of the conditional limitations (21), children with SSPI also showed a wide range of communicative functions like their verbal counterparts. Most of the functions elicited by the children with SSPI were basic communicative functions that could be achieved with unaided strategies and ones which did not necessarily require verbal ability. This supports the findings of Bloom and Lahey (4), that certain communicative functions in the early development period is attained through nonverbal means. Cress et al. (11) observed that parents tend to engage more frequently in social play than object based play and they used fewer directives as compared to object play tasks, while interacting with their children with SSPI. This could be one of the reasons for a wide range of communicative function to exist, in spite of the conditional limitation.

**Requests:** Requests had a total mean of 11%, which included 1% of request for information and request for individual attention, whereas request for object had the highest mean percentage of 10% in this category. A higher mean percentage for request for object reflects the ability of the child to choose an activity or material of interest in the presence of severe conditional limitations. Presence of request for information during communication interaction with children with SSPI reflects their curiosity in exploring the environment, which again is fairly low. Among these, a poorer percentage of requests for attention warrants serious attention, as it seems to be a crucial aspect of language learning. Subtle, unconventional, slow, effortful and inconsistent strategies used by these individuals are often missed out and affect contingent responses by significant partners. Such situations could be eliminated by requesting for attention before initiating communication.

**Information:** From the graph, it is evident that information as a function had a mean percentage of 58%, which is the highest mean among the functions listed. A higher mean percentage of information probably reflected the choice of the task in the interaction process, wherein the subjects were expected to provide information. It is likely that certain functions used by the mother especially a higher frequency of request for information could have forced the child to provide a higher frequency of information as compared to any other functions.

**Denial:** Denial had a mean percentage of 29%. A fairly higher occurrence of denial function emphasises the individual's ability to decline what he did not prefer to do or his inability to perform a task which the mother expected him to carry out. This highlights the dominance

of the partners in choosing an activity or material that is not primarily the subject's liking or which is physically not possible for the individual to perform. If the former is true, then one can infer that partners tended to provide an object, which was not asked for by the subjects leading to higher proportion of denial by them.

**Instruction (for action):** Instruction for action had a low mean percentage of 1%. It is possible that children with SSPI are probably not aware that they can manipulate their environment/conversational partner by instructing them to carry out an activity which they prefer and in a fashion that they like. The presence of low mean of instruction (for action) could also be indicative of the passivity of children in terms of manipulating the environment to their preference and following to some extent, the lead offered by mothers. There is a high probability that children actually instructed the mothers to carry out an action, but the non-verbal strategies were, subtle, unconventional or ambiguous, causing a likelihood of being missed out by the mothers. It is also likely that instruction for action is a difficult function for which nonverbal ability is not sufficient enough.

The lower occurrences of some of the functions such as requests for attention, or requests for information or instruction for action could be a result of limited interaction possibilities with the environment due to motor dysfunction. This, in turn might prevent acquisition of communication skills necessary to take part in more complex communicative interaction later in life. Reduced percentage of request for information and instruction for action, again highlights the passivity of the subjects either forced on them due to the condition or the communicative pattern.

## **CONCLUSION**

The study found a varied and fairly high proportion of communication function in the SSPI children in the absence of speech. This study supports the notion that basic communicative functions exist in children in spite of the limitations imposed by their conditions and that such functions are acquired in a different manner (13, 21) as compared to typically developing children. These functions can be well elicited with naturally available nonverbal communicative strategies.

The credit can also probably be attributed to a great extent to the partners who are sensitive and responsive to children's communicative attempt. Partners, especially the mothers tend

to respond to children's communicative attempt in a contingent, consistent and appropriate manner. Since the initial period of communication development is dominated by non verbal communication and it is only later that the verbal component develops, parental responses basically strengthen the belief that speech will develop over time. Parents tend to interact in a fashion that is appropriate to children at the lower age range and who are using non-verbal communication in the developmental period. Since communication is context based, the higher prevalence of certain functions over the others could be strongly linked to the context in which it occurs. Context with reference to communication generally includes not just the situation of occurrence, but also the partner involved in the interaction. These functions were evident during interactions with the mothers and generalisation of these findings to other communicative partners, needs, further studies involving varied partners such as mothers along with other primary caregivers, teachers and peer groups. Though these children do not communicate at par with their verbal counterparts, the findings of this study provide preliminary information about the communicative functions elicited by these children. The findings of this study could be used for deciding the rehabilitation strategies for further communication development.

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**ANNOUNCEMENT FOR THE WELLESLEY BAILEY AWARDS 2009**  
**The Leprosy Mission International**

The Leprosy Mission International (TLMI) invites nominations for the sixth round of Wellesley Bailey Awards. The Awards will be presented in the first week of June 2009 at a unique awards ceremony in Canada. The Awards are presented to people who have had leprosy and who have made an outstanding contribution to society. The person nominated must have shown courage and achievement in overcoming the challenges faced through leprosy.

Two separate awards will be given, preferably to one male and one female. Unsuccessful nominations from previous years can also be submitted for reconsideration. Whether or not the nominee is informed is at the discretion of those making the nomination. Self-nominations will not be accepted. The deadline for nominations is **Monday 1st December 2008**.

Further information and background information can be obtained from the following website: <http://www.leprosymission.org/web/pages/leprosy/awards2009.html>

or from : Glynis Forbes, The Leprosy Mission International, 80 Windmill Road, Brentford, Middlesex TW8 0QH, United Kingdom, Tel: +44 (0)20 8326 6767, Fax: +44 (0)20 8326 6777, Email: WellesleyBaileyAwards2009@tlmint.org

## **DEPRESSION AND QUALITY OF LIFE AMONG CAREGIVERS OF PEOPLE AFFECTED BY STROKE**

Touseef Khalid,\* Rukhsana Kausar

### **ABSTRACT**

*The aim of this study was to investigate depression and quality of life among caregivers of people affected by stroke. It was hypothesised that caregivers would exhibit high level of depression and that there was negative relationship between depression and quality of life among caregivers. The sample comprised of 25 caregivers of people affected by stroke. Hospital Anxiety and Depression Scale and WHO Quality of Life Scale were administered to assess depression and quality of life respectively. It was found that almost half of the carers were depressed while some of them were at risk of developing depression, and that depression affected their quality of life.*

### **INTRODUCTION**

The present study was conducted to investigate depression and quality of life among caregivers of people affected by stroke. It has been argued that caregivers are the backbone of the service provided to people affected by stroke. A caregiver has to do a number of things, for example, lifting, turning him or her in bed, bathing, dressing, feeding, cooking, shopping, paying bills, giving medicines, keeping him or her company, providing emotional support etc (1). The shift from institutional care to community care makes the impact of stroke caregiving more profound than ever before.

Stroke is the third leading cause of death and the most common disabling disease. The amount of time a caregiver spends helping people affected by stroke and the caregiver's state of health are significantly associated with the level of strain and depression (2). The spouse, children and siblings are visually identified as caregivers (3). Stroke caregivers have a high risk of depression and psychological morbidity, and they perceive caregiving as

a burden in terms of feelings of heavy responsibility, uncertainty about care needs, constant worries, restraints in social life, and feelings that the affected persons totally rely on their care (4). Depression is an effect of caregiving that has been widely examined and reported among caregivers, especially among women and those younger in age (3). Kausar (5) examined the relationship of the carer's primary appraisal (stress, threat, challenge and centrality), secondary appraisal (carers' perception of caregiving as control by self, control by others and uncontrollability) and coping strategies in carers of physically disabled persons in Pakistan. Results indicated that the carer's primary appraisal of concerns and worries about physical disability had a strong relationship with anxiety and depression in carers. Financial concerns and carer-patient relationships were strong predictors of depression in carers.

A study on depression in caregiver spouses of people with cancer (6) in Pakistan revealed that female caregiver spouses manifested more depression than males. Depression severity is the greatest predictor of poor quality of life. In analysing reports of 256 carers, it was found that caring for an incapacitated individual worsened health, impaired social and family life and increased stress, anxiety and depression among carers (7). Caregiver Quality Of Life (QOL) was adversely influenced by disability of the affected person and by the caregiver's age, gender, and physical health (8). Another study on quality of life in people affected by stroke and their partners, found the impact on the QOL of partners, prominently in the psychosocial domains. This is in keeping with increased emotional distress found in spouses or caregivers of people affected by stroke in general. Partners reported feelings of anxiety and uneasiness (9).

Based on the earlier literature, it was hypothesised that caregivers of people affected by stroke, exhibit high level of depression, there is a negative relationship between depression and quality of life among caregivers of people affected by stroke and that there is a negative relationship between depression and physical, psychological and social quality of life of caregivers.

## **METHOD**

### **Participants**

The sample comprised of 25 caregivers of people affected by stroke: 17 male caregivers and 8 female. The caregivers' age range was from 21 to 45 years and only younger adults were

included because older adults may not have been able to provide care to the affected persons and old age itself might pose health problems. All the caregivers were educated enough to understand questionnaires in Urdu language. Any type and severity of stroke was included but caregivers with any past psychiatric illness, severe physical illness or who were uneducated, were excluded.

### **Measures**

A detailed demographic questionnaire was used for getting the demographic information, which was developed by the researcher.

The Hospital Anxiety and Depression Scale (HADS) is a self-assessment scale that has been developed and found to be a reliable instrument for detecting states of depression and anxiety in the setting of a hospital medical outpatient clinic. The scale was originally developed in English (10). The HADs contains 14 items and consists of two subscales: anxiety and depression. In the present study only those items were used which measure depression. HADS was translated into Urdu by the researcher.

The WHO Quality Of Life Scale (QOL) was developed by the WHO QOL group in 1996 (11), containing 26 questions. The four domain scores denote an individual's perception of quality of life in each domain. WHO QOL scale was translated into Urdu by the researcher.

### **Research Design**

Correlation research design/within subject design was used in this research to find out the relationship between depression and quality of life among caregivers of people affected by stroke.

### **Procedure**

After obtaining official permission from hospitals, caregivers were approached with the help of concerned doctors. Informed consent was taken from those participants who agreed to participate and fulfill the required criteria. The researcher briefed the participants about the research process, took their written consent and assured them of the confidentiality.

## RESULTS

In the present study, carers were categorised according to the degree of severity of depression that they reported. Categorisation was under categories of normal, borderline and depression as per the procedure prescribed in the manual of HADS.

Results showed that almost half the caregivers were depressed (48%) and a quarter scored at the borderline (24%) i.e. they were at risk of developing depression (Table 1).

**Table 1. Level of Depression among caregivers (N=25)**

Levels of Depression	Frequency	Percentages	$\chi^2$	P
Normal	7	28%	2.48	.298
Borderline	6	24%		
Depressed	12	48%		

Caregivers' score on the QOL scale showed that carers scored lower on social QOL and psychological QOL indicating that caregiving responsibility had adversely affected social and psychological health of carers (Table 2).

**Table 2. Descriptive statistics of Quality of Life and its dimensions (N=25)**

	Mean	Standard Deviation
Total	83.00	13.74
Environmental (QoL)	23.88	5.36
Physical (QoL)	23.08	3.62
Psychological (QoL)	18.72	3.42
Social (QoL)	10.24	2.42

Creational analysis was carried out to examine relationship between carers' quality of life and depression. Results indicated that there is a negative relationship between quality of life and depression (Table 3).

**Table 3. Correlation between Depression and Quality of Life (N=25)**

	Scores of QOL	Physical Dimension	Psychological Dimension	Social Dimension	Environmental Dimension
Depression	-.581**	-.404*	-.515**	-.467*	-.569**

p<.05\* p<.01\*\*

Further analysis revealed that caregiver's age had negative relationship with social quality of life indicating that social quality of life of younger carers was adversely effected. The affected person's age had a negative relationship with the carer's depression. Carers of younger patients experienced more depression. Moreover, the carers income had significant negative relationship with depression (Table 4).

**Table 4. Correlation between Caregiver's age, Caregiver's Monthly income, Affected person's age, Depression and Quality of Life (N=25)**

	Score of HADs	Score of QOL	Physical Dimension	Psychological Dimension	Social Dimension	Environmental Dimension
Caregiver's Age	-.021	-.297	-.265	-.160	-.396*	-.076
Caregiver's Monthly Income	-.404*	.360	.198	.305	.333	.371
Affected Person's Age	-.454*	.344	.357	.326	.258	.266

## **DISCUSSION**

Results of the study revealed that almost half the caregivers of people affected by stroke were experiencing depression and about a quarter were at risk of developing depression. The findings are consistent with earlier research (12) which revealed that caregivers reported depression even more than the affected persons themselves.

This study found that there was a negative relationship between the depression and QOL among caregivers and there is significant relationship with total QOL as well. Caregiver depression was best predicted by lower life satisfaction, lower physical functioning, and a lack of tangible social support (7), but the physical dimension relationship between depression and QOL was not significant in this study as compared to other dimensions because caregivers included in this study were healthier and did not have any physical and psychological ailment. Caregivers' social QOL showed less correlation with depression as compared to other dimensions and the reason could be that in Pakistan more social support is available and most of them were satisfied with their personal relationship and support received by their family members and friends. However their social life is affected because of the responsibility and time spent on caregiving. Similarly, Rhodes, Lin, and Streiner (13) found that social isolation was related to both caregiving and depression. Caregiving leads to isolation, which in turn leads to depression.

Psychological dimension of QOL was significantly negatively correlated with depression. While environmental dimension of QOL showed high negative correlations with depression, it indicated that participants were not happy with their surroundings and did not have a conducive environment such as residential and transportation facilities.

Monthly income of caregivers has a negative relation with depression and thus due to lack of a monthly income, QOL also suffers. Less income relates with depression because of economic strain. Carers who have lower incomes and less facilities experience particular difficulties (7).

Due to the heavy burden and responsibilities, carers of people affected by stroke experience depression and depression affects the QOL. Almost half the carers showed depression while some of them were at risk of developing depression. Caregivers' psychological health is at heightened risk and social life becomes limited as well. Their physical health is also affected

and satisfaction with the environment is also reduced. Patients' age also contributed to depression. Caregivers' age affects their social QOL.

This study highlights the importance of provision of psychological services for caregivers. This study can be effective for counselling and any possible intervention of caregivers, so that they can provide effective care to the people affected by stroke and can maintain their own emotional health and quality of life.

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## **PARENTAL ATTITUDES TOWARDS CHILDREN WITH HEARING IMPAIRMENT**

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### **ABSTRACT**

*The present study was undertaken to investigate the attitudes of parents towards their hearing impaired children. The sample comprised of 60 parents (30 fathers and 30 mothers) of 0-12 year old hearing impaired children, in and around Mumbai, India. "Parental Attitudes Scale" a self-assessment tool was specially developed for the purpose of the study. The scale has a reliability of .67, consisting of 33 statements. Results indicate that there is significant difference between the fathers and mothers' attitudes with the fathers exhibiting more favourable attitudes towards male children. The findings of the study indicate the importance of counselling focused specifically towards developing healthy parental attitudes which would in turn result in acceptance of the child's disability and facilitate therapeutic progress.*

### **INTRODUCTION**

There are 21.54 million children with hearing impairment in India, caused by inadequate healthcare or ear care. Of this number, it is estimated that 8.15 million are school children (1).

For a parent who has practically no knowledge about deafness and has a child stigmatised as "deaf and dumb", this can be a shattering experience particularly as it so often happens, "the cause is unknown." The first reactions are usually panic, guilt, blame and despair. They strive to understand the disability and its implication. They struggle to cope with their own emotions and the reaction of others. Their attitudes towards their child change, resulting in changes in responses towards the child.

These attitudinal changes in turn may have an adverse effect on the child. For hearing parents, it is a very difficult task to accept the disability. Once they come to know about the diagnosis of deafness, they are shocked and traumatised. Parents may start developing

negative attitudes towards the child after the diagnosis, which may not have been present prior to the diagnosis. Their behaviour patterns too, might change.

Dharitri and Vinoda (2) studied behaviour problems in hearing impaired children and parental attitudes. They studied three groups consisting of hearing impaired children attending special school, hearing-impaired children attending regular school and children without impairment. They concluded that hearing impaired children showed more behaviour problems. Some of the behavioural problems increased with age. Mothers of the hearing impaired children showed some favourable attitudes and some negative attitudes.

Umadevi and Venkatramaiah (3) studied attitudes and aspiration of parents towards their deaf children. Family interactions were found to be good in a majority of cases. Parents had higher aspirations for their deaf children and a majority wanted their children to be settled in jobs and to lead an independent life. Charanjeev (4) reports that parents felt that their acceptance would enable the child to be better adjusted, feel confident and secure and get along well with everyone.

The parents of newly diagnosed hearing-impaired children may experience guilt, which is manifested in several ways (5). The period immediately following the diagnosis was found to be particularly stressful for parents. Mourning “the lost normal child” leads to shock, recognition, denial, acknowledgment and constructive action (6). Parents can look at the positive aspects of their child’s in the family. The child can create opportunities for family bonding and growth for each individual member (7).

## **METHOD**

The present study attempted to assess the attitudes of parents of hearing impaired children, just after the diagnosis of the impairment.

The sample comprised of 60 parents, 30 fathers and 30 mothers of hearing impaired children attending speech-language therapy, who fulfilled the following criteria:

- i. Spouse should be alive, ii. neither parent of the child should be a step parent, iii. the child should have congenital or acquired hearing loss before the acquisition of speech and language, iv. child should have average intelligence, v. child should have stayed with parents since

birth, vi. child should not have any associated problem, vii. child's siblings should be free from any serious impairments, viii. the child should be in the age range of 0-12 years.

A 35 item questionnaire was developed in English and was given to 3 judges with 15 years or more of experience in the field of speech and hearing. Necessary changes suggested by the judges were incorporated in drawing up a final version of the questionnaire with 33 items. Secondly, the associated set of instructions were framed. The questionnaire was also translated in the local language. Reliability exercise was carried out for the questionnaire. Guttman split-half reliability is .6651 and unequal-length Spearman Brown' reliability is .67 which indicates questionnaire is reliable for research purpose.

Parents were oriented about the purpose and confidentiality of the study before administering the questionnaire and consent was obtained. Parents were individually administered the questionnaire according to their preferred language. Identification data were collected about age, sex, education, occupation, and income.

The direction of the statement determined the response i.e., "Yes" or "No". Based on the directionality of the statement, 22 'Yes' items secured a score of one and 11 'No' items secured a score of one. Total maximum score obtainable was 33. Higher the score, the more positive/favourable the attitude, and lower the score the more unfavourable the attitude.

## **RESULTS AND DISCUSSION**

The data collected from the sample were subjected to statistical analysis. The sample of the study comprised of 60 parents, 30 fathers with a mean age of 33.43 years and 30 mothers with a mean age of 28.9 years. Kolmogorov-Smirnow goodness of fit test indicates that the scores are normally distributed at p-value .247. On the parental attitudes scale a minimum score of 17 and maximum score of 31 was obtained with a mean score of 25.45 and standard deviation of 3.35.

As table 1 indicates, mean score of fathers at 26.2, is higher than that of mothers (24.7). It can be inferred that fathers exhibit more favourable attitudes towards children with hearing impairment in comparison with mothers. It is further established that the difference in means between attitudes of mothers and fathers is significant at  $p < .05$ .

**Table 1. Attitudes of fathers and mothers**

<b>Parents</b>	<b>Mean</b>	<b>SD</b>	<b>t-value</b>
Father	26.2	3.25	1.77
Mother	24.7	3.32	

This finding could be attributed to the mother's expectation of an ideal child, and may also be a reflection of the mother's mourning for the lost "ideal" child. Another could be that since child care in the Indian context almost exclusively rests on mothers, the intensive contact could in fact be leading to maternal burn-out or fatigue, and this could in turn probably lead to unfavourable attitudes towards the child. Another reason is that, the average Indian mother is more emotionally dependent on her child as compared to the father and her disappointment with a disabled child may be more.

Table 2 shows the mean score of parental attitudes for male children is 26.16 and for female children is 23.95, which suggests that parents exhibit more favourable attitudes towards male children in comparison to female children. However, the obtained t-value 2.44 is not statistically significant.

**Table 2. Parental attitudes towards male and female children**

<b>Child</b>	<b>Mean</b>	<b>SD</b>	<b>t-value</b>
Male (n=36)	26.16	3.04	2.44
Female (n=24)	23.95	3.96	

As table 3 shows mean scores for male children is higher than that for female children, that is, fathers exhibit more favourable attitudes towards male children in comparison with female children. The obtained t-value is statistically significant at  $p < .05$  level. This differential preference may well be a reflection of the cultural bias favouring male children.

**Table 3. Fathers' attitudes towards male and female children**

<b>Child</b>	<b>Mean</b>	<b>SD</b>	<b>t-value</b>
Male n=17	27.33	2.48	2.11
Female n=13	24.84	3.71	

Table 4 depicts the attitudes of mothers towards their male and female hearing impaired children. The mean score of mothers towards male children is somewhat higher than the mean score of female children. The obtained t-value is not significant at  $p < .05$ . This finding is partially in consonance with the unusual finding of Kurian (8), who reported no significant difference between parents of boys and girls and further supports the cultural preference for the male child.

**Table 4. Attitudes of mothers towards male and female children**

<b>Child</b>	<b>Mean</b>	<b>SD</b>	<b>t-value</b>
Male n=19	25.31	3.18	1.35
Female n=11	23.63	3.43	

An analysis of birth order with reference to parental attitudes suggest that there is a negative but low ( $r = -.23$ ) correlation. First born children enjoy more favourable parental attitudes in comparison to those born later. The result indicates this relationship at  $P = .035$ . The difference in attitudes may be attributed to the expectations and excitement of parents with regard to the birth of the first child and is probably not paralleled again.

Analysis of variance was applied to analyse the difference in parental attitudes for three different education levels. Table 5 indicates that there is a significant difference among the different educational levels at  $p < .05$ . It may be inferred that as the education level of parents increases, the attitudes towards their children with hearing impairment becomes more favourable.

**Table 5. Education levels of parents and parental attitudes**

<b>Educational level</b>	<b>Number</b>	<b>Mean</b>
Below Class 10	27	24.29
Class 10-12	20	26.15
Graduates and above	13	26.76

The difference between attitudes of parents with lower educational level and those of graduate parents and higher educational qualifications is significant at  $p < .05$ . Similar trend is reported by Kurian (8) who reports a significant difference in parental attitudes between the lowest and higher socio-economics groups. One possible reason could be that more educated people are more likely to be able to acquire greater levels of information about disability, rehabilitation measures and resources, and can access the latest medical and rehabilitation help available.

## **CONCLUSION**

The conclusions of the study are: 1) fathers exhibit more favourable attitudes in comparison to mothers 2) fathers and mothers exhibit more favourable attitudes towards their hearing impaired sons than towards their daughters. However, this attitudinal bias is statistically significant in case of fathers, but not so with mothers. As education levels improve, parental attitudes also become more favourable.

Since parental attitudes play an important role in the rehabilitation of any disabled child, it may be desirable to include the "Parental Attitude Scale" as a screening tool along with other audiological, speech and psychological assessment. The scale could help in understanding parental attitudes and feelings about their hearing impaired children and serve as a guideline for counseling parents to bring about the attitudinal changes for more effective rehabilitation.

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CONTENTS

Vol. 19 ■ No. 2 ■ 2008

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Editor's Comment ..... 1

## GUEST EDITORIAL

### **Considerations in the Quest for Evidence in Community Based Rehabilitation**

*Pim Kuipers, Steve Harknett* ..... 3

## DEVELOPMENTAL ARTICLES

### **Exclusion of Disabled People from Microcredit in Africa and Asia: A Literature Study**

*J.M. Cramm, H. Finkenflügel* ..... 15

## ORIGINAL ARTICLES

### **The Development of a Resource Guide on Post Traumatic Stress Disorder for Rural Health Care Workers**

*Tiziana Bontempo, Lauren Westmacott, John Paterson, Margo Paterson* ..... 34

### **Disability Among Clients Attending Taif Rehabilitation Centre, Saudi Arabia**

*Abdul-Salam A. Al-Shehri, Moataz M. Abdel-Fattah* ..... 50

<b>Psychosocial and Demographic Correlates of Academic Performance of Hearing-Impaired Adolescents</b> <i>Sujata Satapathy</i> .....	63
<b>A Remedial Teaching Programme to help Children with Mathematical Disability</b> <i>C.N.Karibasappa, Surendranath P. Nishanimut, Prakash Padakannaya</i> .....	76

#### BRIEF REPORTS

<b>Communication Functions in Children with Severe Speech and Physical Impairment</b> <i>Preeja Balan, R. Manjula</i> .....	91
<b>Depression and Quality of Life Among Caregivers of People Affected by Stroke</b> <i>Touseef Khalid, Rukhsana Kausar</i> .....	103
<b>Parental Attitudes Towards Children with Hearing Impairment</b> <i>Suman Kumar, Geeta Rao</i> .....	111

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